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National University of Ireland, Cork  
Ollscoil na hÉireann, Corcaigh



## **Caregiver readiness for hospital discharge of an older adult**

Thesis presented by:

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Submitted as fulfilment of the requirement for

**Master's Degree by Research**

**April 2020**

**Catherine McAuley School of Nursing and Midwifery**

**Brookfield Health Sciences Complex**

**University College Cork**

**Supervisors: Dr Teresa Wills & Dr Mairin O'Mahony**



## **Declaration**

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I declare that the content of this assignment is all my own work. Where the work of others has been used to augment my assignment it has been referenced accordingly. I attest that I have not submitted this material in whole or part for the assessment of another programme or award in this University or at another higher education institution.

**Signed**            Eileen Galvin

**Date**             27 April 2020

**Word count:**   41,207

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*For Barry*

## Abstract

**Aim:** To explore caregiver readiness for the hospital discharge of an older adult.

**Background:** Older adults rely on their caregivers during hospital discharge. However, caregivers are not routinely included in discharge preparation. Caregivers' experiences of hospital discharge have been studied retrospectively between one week and three months. However, no study used the attributes of readiness to guide the research and none of the caregivers were interviewed within twenty-four hours of hospital discharge when experiences are foremost in their minds.

**Method:** The study was qualitative descriptive. Using the attributes of readiness for hospital discharge to develop an interview guide, nine semi-structured interviews with caregivers took place within 24 hours of hospital discharge during the summer of 2017. Data were analysed using content analysis.

**Findings:** The findings that emerged from the data are presented under the four attributes of readiness for hospital discharge: Caregivers' physical readiness, Caregivers' psychological readiness, Support for caregivers and Information and knowledge. An overarching category of "Wanting to do what's best" also emerged. Findings highlight that overall, caregivers are not ready to take the older adult home from hospital. In addition, low referral rates of older adults to PHN services were highlighted.

**Conclusion:** The results of this unique study provide a picture of the current state of caregiver readiness for the hospital discharge of an older adult. In addition, the need for early preparation of caregivers for the hospital discharge of an older adult is highlighted which includes early referral to PHN services.

**Impact:** Nursing staff require focused education on the preparation of caregivers for hospital discharge. In addition, development of a tool to assess caregiver physical and psychological readiness is necessary. Further research and assessment of caregivers longitudinally will give more insight into caregiver needs, experience and progress. Ultimately, ensuring caregivers are ready for hospital discharge of an older adult will assist older adults remaining at home, which is ultimately where they want to be.

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## **List of abbreviations**

ADL's	Activities of Daily Living
CPD	Continuous Professional Development
DePART	Discharge Process Acute Rehabilitation Transition
ED	Emergency Department
GP	General Practitioner
HCP	Health Care Provider
MMAT	Mixed Methods Appraisal Tool
PDCT	Post Care Transition Program
PHN	Public Health Nurse
PT-RHDS-SF	Patient - Readiness for Hospital Discharge Scale – Short Form
QDTS	Quality of Discharge Teaching Scale
QoL	Quality of Life
RCT	Randomised Controlled Trial
READI	Readiness Evaluation and Discharge Intervention
RHDS	Readiness for Hospital Discharge Scale
RN	Registered Nurse
RN-RHDS	Registered Nurse - Readiness for Hospital Discharge Scale

RN-RHDS-SF      Nurse - Readiness for Hospital Discharge Scale - Short Form

SD                  Standard Deviation

US                  United States

## Introduction

Family members and informal caregivers are an essential component of healthcare (Epstein-Lubow 2012, Family Carers Ireland 2018). Currently, one in twenty people in Ireland are caring for a family member; this will rise to one in five by 2030 (CSO 2016). Caregivers are defined as “a person who has accepted responsibility for looking after a vulnerable neighbour or relative also called a carer” (Collins 2014, p.312).

Caregivers of older adults provide a range of care with activities of daily living, medical decisions and importantly assistance in the area of transition between settings of care such as hospital to home. The Irish Government and Health Care Policy on Family Carers/Older People (HSE 2011) acknowledge that informal/Family caregivers provide frontline support and care to older adults in the community and indicate the situation is similar in the United Kingdom. Figures in Ireland indicate 51% of those aged 85 years and over are being cared for by informal caregivers in the home (CSO 2012). Half of the 50-64 year old population of Ireland provide help with household tasks to their parents and over a quarter provide their parents with personal care (Care Alliance Ireland 2015).

Informal caregivers assist older adult patients with continuing medical needs and many daily activities when discharged from hospital (Coffey and McCarthy 2013). Numerous studies have indicated the inclusion of caregivers is an important part of discharge preparation of the older adult ( Boughton and Halliday 2009, Bobay *et al.* 2010, Fitzgerald *et al.* 2011, Perry and Middleton 2011, Brent and Coffey 2013, Gustafsson and Bootle 2013, Young *et al.* 2014, Rodakowski *et al.* 2017). However, caregivers are not routinely included in discharge preparation and caregivers are not routinely assessed to take home an older adult at the time of hospital discharge (Young

*et al.* 2014, Wolff *et al.* 2017). In addition, no assessment tool exists to measure caregivers' level of readiness at the time of hospital discharge (Tyler *et al.* 2014, Young *et al.* 2014).

Comparing caregivers with patients, Shin *et al.* (2011) identified that not one single domain of caregiver needs for hospital discharge were correlated with patient needs. Therefore, caregivers require their own assessment, and it cannot be assumed that caregivers of low need patients experience fewer needs. Better preparation of caregivers is essential to sustain their caregiving role and is pivotal to the success of home care for an ageing population (Toye *et al.* 2016).

Research exploring caregivers' experiences caring for older adults after hospital discharge thus far has been retrospective, with data collection points ranging from one week to three months post discharge. Therefore it was decided that caregiver readiness within 24 hours of the hospital discharge warranted further exploration because this specific timeframe is when thoughts, feelings and caregiver needs are at the forefront.

### **Context of study**

Adults over 65 years of age account for 20% of all hospital discharges in Ireland (ESRI 2012). By 2041 the population of Ireland aged 65 and over will have doubled (ESRI 2012). These figures indicate that problems for caregivers will increase. To combat problems for caregivers, policies and practices to assist caregivers to be ready for the hospital discharge of the older adult are necessary. In addition, the International Society for Quality in Health Care (ISQua) continue to argue for refashioning health systems in response to ageing (Braithwaite *et al.* 2018).

Hospital discharge is a controversial topic, with much national news coverage generating weekly statistics. Early discharges are caused by the pressure of financial

drivers and lack of hospital beds (Hesselink *et al.* 2012). As a result, older adults are discharged from hospitals earlier than ever before. This requires preparation for hospital discharge to take place over a shorter length of time (Rodakowski *et al.* 2017). Consequently, the burden of post discharge care of older adults falls on caregivers (Care Alliance Ireland 2013, Neiterman *et al.* 2015, Rustad *et al.* 2017).

Readmission rates have become an important quality of care measure (Weiss *et al.* 2011, Lau *et al.* 2016) and poor discharge preparation can place pressure on hospital services because of unscheduled Emergency Department (ED) visits and readmissions (Bobay *et al.* 2010, Weiss *et al.* 2011, Weiss *et al.* 2014). In Ireland, several strategies have been introduced surrounding patient discharge. However, recent figures show emergency re-admissions for acute medical conditions, to the same hospital within 28 days of discharge, were 11% in 2014, and 10.7% in 2015 (HSE 2015).

Caregiver integration in discharge planning of older adults has resulted in 25% less readmissions within 90 days (Rodakowski *et al.* 2017). Therefore, incorporating caregivers in discharge planning could have a significant effect with potentially preventable 30-day readmissions which have been estimated to cost \$12 billion annually in the US (Rodakowski *et al.* 2017).

Discharge planning is usually disease specific but discharge planning programmes of older adults could be enhanced to include caregivers (Rodakowski *et al.* 2017). However, as the needs of older adults post discharge are varied and complicated, we need to ensure that caregivers are ready to take the older adult home. Previous studies have shown the importance of readiness for hospital discharge among medical surgical adult patients (Weiss *et al.* 2007), parents (Weiss *et al.* 2008) and the older adult (Bobay *et al.* 2010) but no study exists on caregiver readiness for the hospital



discharge of an older adult. Understanding what caregivers require at the time of the older adults hospital discharge, will assist in the development of policies to guide clinical practice, instrument development and further research in the area.

Therefore, to address the issue, this thesis begins at chapter one, by conducting a concept analysis of readiness for hospital discharge. This chapter presents antecedents, attributes and consequences as well as an operational definition of readiness for hospital discharge. The result of this concept analysis provides a framework on which to base chapter two which is an integrated review of the empirical literature on readiness for hospital discharge. Chapter two presents the results of the literature review under three headings: Patient perception of readiness for hospital discharge; Healthcare Providers' practices in getting patients ready for hospital discharge and; Caregiver concerns and experiences of hospital discharge.

In chapter three the methodology used to explore caregiver readiness for discharge of the older adult from hospital and the reasoning for the method used are presented. Details regarding choice and access to sample, ethical considerations, data analysis and rigour are provided. The findings are presented in chapter four in accordance to the four attributes of readiness for hospital discharge: Caregivers' physical readiness, Caregivers' psychological readiness, Supports required by caregivers and Information provided to caregivers. In addition, an over-arching category of "Wanting to do what's best" emerged. The thesis will conclude with a discussion on the findings and concludes with the strengths and limitations, and implications for practice, education and research.

# **Chapter 1- Concept analysis of readiness for hospital discharge**

## **Introduction**

The assessment of a patient's readiness for hospital discharge has been identified as a central component of the discharge planning process (Weiss *et al.* 2007, Smith-Johnson *et al.* 2015). Research in the area of hospital discharge is of international relevance, as challenges in relation to hospital discharge are a recurring global theme. Issues such as reducing the cost of healthcare have resulted in a shorter hospital stay (Anthony & Hudson-Barr 2004, Carroll & Dowling 2007, Weiss *et al.* 2007, Balaban *et al.* 2008, Coffey & McCarthy 2013). The result in many cases is that patients are not ready to go home because there is less time for discharge preparation (Weiss *et al.* 2007, Balaban *et al.* 2008).

This chapter describes a concept analysis of "readiness for hospital discharge" using the eight step process by Walker and Avant (2011). There was an absence of a unified definition, and no concept analysis existed on this phenomenon. As the concept examined here is behavioural; concerned with understanding an experience (Cronin *et al.* 2010), the objective of this analysis was to identify which phenomena match the concept of readiness for hospital discharge and which do not.

## **1.1 Background**

The concept of readiness for hospital discharge was initially defined by Fenwick (1979) as the patient's feeling of being prepared to face reality. Steele and Sterling (1992) described patient readiness as an estimate of a person's ability to leave the hospital. Home readiness is a term used in the anaesthesia literature, and describes patients at a stage of sufficient recovery to safely discharge (Korttila 1995). A hospital

discharge is deemed successful if there is increased quality of life (QoL), patient satisfaction and no readmission for the same illness within six weeks (Carroll & Dowling 2007).

Rapid patient turnover results in less time to comprehensively prepare patients for hospital discharge (Anthony & Hudson-Barr 2004). According to Weiss *et al.* (2007) readiness is now a central component of the discharge planning process. Readiness has been identified as an outcome indicator, where poor readiness for hospital discharge leads to readmission (Weiss *et al.* 2010, Weiss *et al.* 2011, Coffey & McCarthy 2013, Weiss *et al.* 2014). Nosbusch *et al.* (2011) convey that preparation for discharge should begin prior to admission and assert that the staff nurse, who has the most contact with the patient, plays a critical role in preparing for home. However, preparation for discharge is time consuming and discharge preparation often appears rushed (Block *et al.* 2014).

There is a multiplicity of professionals involved in the discharge process, all using multiple discharge methods, and all use different criteria for the assessment of readiness for discharge. Professionals are often focused on their own areas of responsibility and formal education on safe transitions of care is not universal. Some educators focus on only one component of the discharge process, such as medication reconciliation (Block *et al.* 2014). Therapy professionals focus on the functional capacity of patients as being central to preparation (Clark *et al.* 1997). Fiore *et al.* (2012) discovered that discharge criteria focused mainly on physical readiness and poor consistency in the terminology used to describe readiness for hospital discharge. Nurses have the most frequent contact with patients and are responsible for discharge preparation in most cases (Nosbusch *et al.* 2011, Weiss *et al.* 2011). Thus, Fowler (1998) discussed the necessity of nurses recognising patient readiness, so that

interventions are incorporated into patient care at an optimum time. Carroll and Dowling (2007) asserted that the bedside staff nurse was best placed to co-ordinate hospital discharge, with all other healthcare professionals supporting. Weiss *et al.* (2011) discovered that when patients had more time with the nurse, discharge preparation was more effective.

Lack of patient involvement in the discharge plan can lead to feelings of un-readiness (Anthony & Hudson-Barr 2004). Bobay *et al.* (2010) affirmed that assessment and identification of post discharge needs during hospitalisation prevent problems. To improve the understanding of readiness for hospital discharge a unified operational definition is necessary. Therefore, the aim of this concept analysis was to develop an operational definition of the phenomenon “readiness for hospital discharge”. Other aims were to identify all uses of the concept, to provide conceptual clarity and to provide direction for future research. The Walker and Avant (2011) eight-step process is outlined in appendix 1 and is a modified version of the Wilson (1963) process.

### **1.1.1 Data Sources**

A scoping search was carried out initially, followed by a search of the empirical literature in the following data bases; Academic Search Complete, CINAHL Plus with Full Text, PsycARTICLES, Psychology and Behavioural Sciences Collection, PsycINFO, Social Sciences Full Text (H.W. Wilson), SocINDEX with Full Text. Articles were not excluded by time limit because one of the aims of this analysis was to identify all uses of the concept.

Keywords used in the literature search were: Ready, Readiness, Prepared, Prepare, Preparedness, Preparation, Hospital, Discharge and “Concept analysis”. This search generated 478 hits. Inclusion criteria of importance were English language and

academic journals. As the number of articles were vast, narrowing by subject thesaurus, 160 articles (title and abstract) were examined for relevance. Finally, the reference lists of all identified papers were hand searched for other relevant cited articles. The final number of academic journal articles deemed relevant and included in the concept analysis were 24 articles. A PRISMA flow chart depicting this search is available in appendix 2. The Collins (2014) English dictionary and thesaurus (Collins 2015) were used to provide definitions of the concept.

Using the Walker and Avant (2011) process, papers were first read in their entirety. Then a data extraction table and a computer assisted qualitative analysis package were used to extract and categorize the attributes, antecedents, consequences and related concepts. Initially the relevant studies were grouped by study type; literature reviews (n=3); concept analysis of readiness in other realms (n=3); quantitative studies (n=13) and qualitative studies (n=4). One article depicting a nursing reflection was included as it added valuable nursing insights. The papers were mainly authored by nursing researchers, 3 were authored by medicine researchers and 2 were therapy researchers. The vast majority were of USA origin with Australia, Canada, Ireland, Sweden and Switzerland also represented. A table of literature characteristics is available in appendix 3. The analysis generated the following results.

## **1.2 Results**

### **1.2.1 Uses of the Concept**

Collins (2014) English dictionary define readiness as “a state of completion or preparedness, make ready or get ready or prepare oneself, to put in a state of readiness or to prepare”. Other definitions offered were: prepared and waiting for the guest’s arrival and prepared in advance of use (Collins 2014). Hospital discharge for the

purpose of this analysis is defined in its own right by Collins (2014) as: “to release or allow to go”: the hospital discharged the patient.

Collins (2015) gives the following synonyms for readiness: Willingness, Inclination, Eagerness, Preparation, and antonyms include un-readiness, unpreparedness. The author focused on the following; to get ready as in prepare oneself, the state of being ready and prepared in advance, in the context of leaving hospital or hospital discharge.

In the literature, readiness has been analysed in relation to change. Fleury (1991) determined that individual readiness to change consisted of, re-evaluation of lifestyle, identification of barriers, and commitment. Fowler (1998) examined nursing interventions that assisted patients to incorporate change and discovered that interventions must be presented to patients at a time when the patient's ability to succeed is optimal. They established that the ability to recognise readiness in patients is essential.

Efraimsson *et al.* (2003) asserted that effective communication was central to readiness for discharge but preparation focused mainly on the patient's medical state. Anthony and Hudson-Barr (2004) asked patients about their needs for discharge. Patients rated information about resources, knowledge of their home-going needs, active involvement in the process and medications as most important for readiness to go home.

Carroll and Dowling (2007) suggested that open and honest communication between the multidisciplinary team is required to prepare the patient for hospital discharge. According to these researchers unreadiness for discharge was caused by poor history taking, poor nursing handover, differing opinions on who coordinates the discharge and the quality of communication when educating patients (Carroll and Dowling

2007). Readiness for hospital discharge is usually judged by clinical criteria, although Weiss *et al.* (2007) examined predictors of discharge readiness and found that quality of discharge teaching was the strongest predictor of discharge readiness. Importantly, the perception of readiness may be different between, patient and provider (Weiss *et al.* 2007).

Bobay *et al.* (2010) described patient readiness for hospital discharge as multidimensional. The dimensions include assessment of physical, social and psychological states; understanding their illness, medications, physical limitations and what to expect, as well as community resources and support. They also noted that when patient needs were accurately assessed early in their hospital stay, patient readiness for hospital discharge was more successful (Bobay *et al.* 2010).

According to Rydeman & Törnkvist (2010), professional skills when preparing the patient for home increased the level of discharge readiness and feeling prepared meant having a satisfactory conception of how life at home would be. Caring issues, activities of daily living and where to turn for support were deemed most important in feeling prepared. Fiore *et al.* (2012) discovered 70 different sets of criteria to indicate readiness for discharge and those most frequently cited were tolerance of oral intake, return of bowel function, adequate pain control and adequate mobility.

Weiss *et al.* (2011) established that adequate staffing reduced readmissions through quality discharge teaching. When Brent and Coffey (2013) examined patients perception of readiness for discharge among those with hip fracture, higher quality discharge teaching was associated with higher levels of readiness for discharge and readiness levels decreased as age increased. In addition, Brent and Coffey (2013) found that when patients were asked if they were ready for discharge, most answered

yes, but on further investigation using the readiness for hospital discharge scale (RHDS) (Weiss and Piacentine 2006), results showed a much lower degree of readiness, indicating that a more in-depth assessment of patient readiness is a necessary part of the discharge process.

Weiss *et al.* (2011) suggested that felt readiness reflected the patient's reality and Coffey and McCarthy (2013) found that a lack of home support was a barrier to discharge readiness. At discharge, differences in readiness existed as age increased and a lower perception of readiness at discharge increased the use of supports post-discharge (Coffey and McCarthy 2013). Weiss *et al.* (2014) also established that nurse assessment of low discharge readiness was associated with an increase in readmission. While in obstetrics, Malagon-Maldonado *et al.* (2015) found that maternal/infant length of stay, delivery mode, and the quality of discharge teaching were predictive of readiness for hospital discharge.

This exploration of multiple uses of readiness and readiness for hospital discharge, allowed identification of multiple and related uses of the concept, which are helpful in defining the attributes (Walker & Avant 2011).

### **1.2.2 Attributes**

Walker and Avant (2011) define the term 'attributes' as characteristics that must always be present if the concept exists and concepts are generally expressed in statements that indicate what are considered to be the attributes. Collins (2014) defines an attribute as a verb, "belonging to" or "linked to". The following attributes belonging to readiness for hospital discharge were extracted from the literature; physical stability, adequate support, psychological ability and adequate information and knowledge.



The first and most acknowledged attribute is physical stability. Stable vital signs, adequate intake and output, normal elimination, adequate ambulation, minimal bleeding, pain control, absence of nausea or vomiting, functional ability and competence to manage self-care at home were the most cited physical signs of readiness for discharge (Anthony & Hudson-Barr 2004, Weiss & Piacentine 2006, Weiss *et al.* 2007, Bobay *et al.* 2010).

The attribute of psychological ability is the influence of preparation on the mental make-up of the individual, causing the desired feeling of readiness for hospital discharge (Collins 2014). Felt readiness is the patient's reality and their conception of life at home influences their psychological level of readiness (Coffey & McCarthy 2013). Psychological ability requires the patient to cope and retain control (Efrainsson *et al.* 2003, Carroll & Dowling 2007, Bobay *et al.* 2010). Awareness of ability and a need to be self-reliant are part of self-perceived readiness (Fowler 1998, Dalton & Gottlieb 2003, Efrainsson *et al.* 2003, Weiss & Piacentine 2006, Weiss *et al.* 2007, Balaban *et al.* 2008, Weiss *et al.* 2011, Coffey & McCarthy 2013).

Collins (2014) described support as giving aid or courage, therefore, the attribute of adequate support is both physical and psychological. Knowing what support was available assisted patients in feeling ready (Weiss & Piacentine 2006, Rydeman & Törnkvist 2010, Weiss *et al.* 2011, Fiore *et al.* 2012, Mabire *et al.* 2015b). Support comes from many sources including friends and family, nurses and other members of multidisciplinary teams and voluntary services. An adequate support system is a positive force in feeling ready (Dalton & Gottlieb 2003, Efrainsson *et al.* 2003, Weiss *et al.* 2007, Brent & Coffey 2013), post discharge supports including General Practitioner (GP) and the Public Health Nurse (PHN) help patients cope with multiple demands after leaving the hospital (Bobay *et al.* 2010).

Information influences readiness (Artinian 1993) and knowledge includes the perceived adequacy of information needed to respond to common concerns and problems during the post hospitalisation period (Mabire *et al.* 2015b). The possession of knowledge in the areas of; caring for oneself, personal needs, medical needs, problems which may occur, who and when to call, physical restrictions, what happens next and available services, are components of feeling ready for hospital discharge (Fowler 1998, Anthony & Hudson-Barr 2004, Brent & Coffey 2013, Mabire *et al.* 2015b). Information was highly associated with how physically ready the person felt, how much they felt they could cope and how much support they expected to have at home (Bobay *et al.* 2010).

### **1.2.3 Antecedents**

Antecedents are those events or incidents that must be in place in order for the concept to occur, and cannot be a defining attribute for that concept (Walker & Avant 2011). According to Dalton & Gottlieb (2003), prior to readiness for hospital discharge, a patient undergoes a self-appraisal, where they decide whether to change from un-readiness to readiness. The patient appraises their situation and weighs the benefit of preparing for readiness, at this stage the patient commits to preparation and identifies the barriers (Dalton & Gottlieb 2003).

When the patient has gained sufficient levels of energy, they begin to prepare, they show desire for involvement and become aware of the benefits of preparation (Clark *et al.* 1997, Anthony & Hudson-Barr 2004, Mainarich & Silverstein 2005, Weiss & Piacentine 2006, Carroll & Dowling 2007, Balaban *et al.* 2008, Bobay *et al.* 2010, Rydeman & Törnkvist 2010, Nosbusch *et al.* 2011, Weiss *et al.* 2011, Coffey & McCarthy 2013, Mabire *et al.* 2015b). The preparation must be patient led (Anthony

& Hudson-Barr 2004), at their pace and level of understanding, because too much too soon can destabilise and prevent readiness (Dalton & Gottlieb 2003).

At this stage contemplation occurs and then action, which involve cognitive and emotional factors as well as commitment (Dalton & Gottlieb 2003). Verbal and written instructions and quality education help the process at this optimum time (Dalton & Gottlieb 2003, Makaryus & Friedman 2005, Bobay *et al.* 2010, Nosbusch *et al.* 2011, Brent & Coffey 2013, Coffey & McCarthy 2013, Mabire *et al.* 2015b). Multiple short episodes of communication can be of more value in preparing or making the patient ready to go home, and skilled delivery is paramount (Bobay *et al.* 2010). Co-ordination of post discharge support is helpful in making the patient ready and builds confidence. This includes detailed clear reports to health and social care professionals, medication reconciliation, and communication with a main carer (Carroll & Dowling 2007, Nosbusch *et al.* 2011, Coffey & McCarthy 2013). The antecedents extracted from the literature are listed in appendix 4, along with the attributes and consequences.

Caring issues, activities of daily living and where to turn were areas of concern by patients in preparation for discharge (Rydeman & Törnkvist 2010). Good physical and emotional condition as "felt" by the patient and enough time given by health providers to achieve this is a must (Anthony & Hudson-Barr 2004, Makaryus & Friedman 2005, Weiss & Piacentine 2006, Nosbusch *et al.* 2011, Fiore *et al.* 2012, Coffey & McCarthy 2013). Ensuring that patients have the skills required to cope at home, ability to adjust to the situation and the confidence to cope with demands takes time (Anthony & Hudson-Barr 2004, Nosbusch *et al.* 2011, Mabire *et al.* 2015b).

Knowing that they have emotional support and instrumental assistance at home assists with any unexpected obstacles. The importance of feeling safe, confident and supported were emphasised (Dalton & Gottlieb 2003, Weiss & Piacentine 2006,

Bobay *et al.* 2010, Rydeman & Törnkvist 2010, Fiore *et al.*, 2012, Coffey & McCarthy 2013). Rushing the discharge process can leave feelings of unpreparedness leading to un-readiness. Therefore, the earlier the preparation is commenced the better the outcome (Nosbusch *et al.* 2011, Mabire *et al.* 2015a).

#### **1.2.4 Consequences**

Consequences are outcomes that occur as a result of the concept and they can shed light on the social context in which the concept is used (Cronin *et al.* 2010, Walker & Avant 2011). There are patient and provider consequences of readiness for hospital discharge.

A sense of control is a positive patient consequence of readiness for hospital discharge (Dalton & Gottlieb 2003). Individual autonomy and power is maintained (Efraimsson *et al.* 2003), satisfaction is gained and there is improved Quality of Life (QoL) (Carroll & Dowling 2007). Nurse-delivered discharge teaching increases self-care adherence and improves clinical outcomes (Bobay *et al.* 2010).

According to Efraimsson *et al.* (2003) safety and security are retained when the patient has adequate family support. In studies of discharge transitions in which older people and their caregivers were encouraged to identify post discharge needs, carers felt more prepared to manage care and received more information about care management (Bobay *et al.* 2010). Positive provider consequences of readiness for hospital discharge are reductions in cost of care and fewer readmissions (Bobay *et al.* 2010).

The literature demonstrates how important readiness for hospital discharge is to the patient in retaining control, autonomy and dignity, as well as feeling safe, secure and supported. None of which can be maintained without the healthcare provider ensuring that the patient is ready to go home.

## 1.3 Cases

### 1.3.1 Model Case

A model case shares all of the key characteristics of the concept, all the defining attributes and at least one of the antecedents and consequences. Ultimately, there should be no overlap or contradictions between the defining attributes and the model case (Walker & Avant 2011).

*Mrs White is a 65-year-old woman who is a planned admission, scheduled for a total knee replacement surgery. She has a son and a daughter, her husband is deceased.*

*During her preadmission assessment, her children are present. A full medical history is taken. Her physical ability is assessed. She meets with the multidisciplinary team who explain the procedure. On admission she is met with the unit staff nurse who orientates her to her surroundings. The nurse initiates communication regarding her living circumstances, and how she is going to manage at home. The nurse also explains that she will not be able to drive until the consultant says she is fit to do so. Mrs White offered to speak about this with her adult children. They discuss taking turns to stay overnight with her, calling before and after work, as well as at lunch time. They may also explore bringing her bed downstairs until she is comfortable with managing stairs on her own. They will arrange to take her to her follow-up appointments.*

*Mrs White speaks to the unit nurse before her operation that afternoon, the nurse records the arrangements she has made with family for support following discharge and arranges to discuss appointments and medications with Mrs White's children. The nurse will also reiterate all discharge instructions verbally and in writing to Mrs White in a couple of days when she is feeling up to discussion.*

*Mrs White has returned to physical stability following her surgery and she expresses that she feels well. Mrs White discusses her care thoroughly with the unit nurse and feels fully informed and knowledgeable about her treatment and care; she attends her physiotherapy and is discharged on schedule. She returns to her consultant at six weeks and is discharged from his care with no adverse events.*

This is a model case because it shows the attributes clearly. Physical stability is met and psychological ability is assessed by the nurse when communication was initiated. Support by the nurse, medical and therapy team as well as family is evident and knowledge of all care is given verbally and in print. The antecedent is the initiation of communication pre and during admission with a consequence of a safe discharge for the patient and family with no adverse events.

### **1.3.2 Related Case**

*Mr Joe was travelling in his wheelchair in a wheelchair taxi. There was a small collision at a roundabout and his car was involved. He was brought by ambulance to the local accident and emergency, where he was examined and deemed to have no injuries and was ready for hospital discharge.*

This related case illustrates the concept, but it differs because Mr Joe was admitted briefly to hospital he did not undergo any treatment, therefore his state of readiness for hospital discharge was not altered by any change in his physical condition. This case assists in understanding the concept, in relation to what comes before the phenomenon (Walker & Avant 2011).

### **1.3.3 Limited Case**

*Mr Black is an 84-year-old man admitted to a large medical ward of an acute hospital at 7pm with a respiratory tract infection. He came to the ward from a busy accident and emergency unit with a brief transfer note stating that he was commenced on IV*

*antibiotics, steroids and nebulisers. The day nursing staff handed over his care to the night staff at 8pm having only seen him briefly to administer his IV antibiotics. There was a different unit team the following day and after the ward round they were informed that Mr Black was to commence oral medications and was discharged home with a neighbour. Mr Black has not received information regarding the management of his medications. He has two inhalers in a box that he has never used before and he is on a reducing dose of another medication. Mr Black has received no information in relation to his follow-up care. Mr Black is breathless which is not normal for him, he lives alone in a two story house where the bathroom and bedroom are upstairs. He is found by his neighbour two days later in a state of delirium.*

The limited case contains one or more but not all the attributes of the concept (Walker & Avant 2011). The case outlined above shows poor physical stability, no adherence to psychological ability and a limited support system in place demonstrating poor readiness for hospital discharge. The patient also got limited information leading to poor knowledge of his situation.

#### **1.4 Definitions of Empirical Referents**

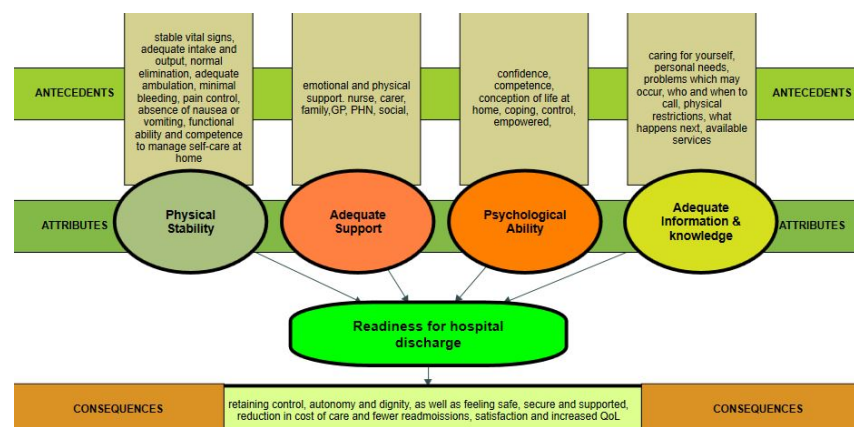
Empirical referents are the means by which the defining attributes or characteristics are measurable (Walker & Avant 2011). They may also point to instruments that are already developed and validated. Confirming that a patient is ready to go home is a difficult task, as readiness is a feeling and feelings are subjective (Mollon 2014). Due to the abstractness of feelings they are more difficult to measure. Probably the best way to find out if a patient is ready for hospital discharge is to ask them, but they may be unable or unwilling to share their true feelings (Mollon 2014).

Few measures have been developed to examine readiness in the context of discharge from hospital. The Readiness for Hospital Discharge Scale (RHDS) developed in the US by (Weiss et al. 2006) is the only instrument that measures an individual's self-perception of readiness before leaving the hospital (Mabire *et al.* 2015b). This scale was specifically developed to measure self-perception of readiness to return home in hospitalised adults, and results of the RHDS scale showed a lower degree of readiness compared to what the patient themselves reported when asked if they were ready (Weiss et al. 2006). This instrument could assist research in other areas of readiness for hospital discharge.

### 1.5 Proposed operational definition

Readiness for hospital discharge is both a state and a process. It is characterised by the person/patient having: physical stability including functional ability and competence to manage self-care at home; adequate support to cope with multiple demands after leaving the hospital; psychological ability, where the patient has become confident enough to manage the transition or process; and has adequate information and knowledge to respond to common problems during the post hospitalisation period. A conceptual map of readiness for hospital discharge is available below (Figure 1).

**Figure 1: Conceptual map of readiness for hospital discharge**





## 1.6 Discussion

The concept “readiness for hospital discharge” was broken into simpler components to determine its internal structure, and because this concept is expressed in words, the analysis was therefore an analysis of the words (Walker & Avant 2011). Examining the uses of a concept is an important process in the cycle of concept development that allows the attributes of that concept to be identified (Walker & Avant 2011). Another important part of concept analysis is the use of cases which exemplify how the concept is naturally and commonly used (Risjord 2009). This analysis of the concept from different perspectives was influenced by a health sciences perspective and the proposed definition is for use in this particular area by a wide multi-disciplinary team in practice and research. This concept analysis is a contribution toward the development of a middle-range theory of clinical reasoning in nursing. Readiness assessments that identify patients at risk of low readiness for hospital discharge will assist nurses and other health care professionals to implement interventions, to increase patient readiness and prevent problematic discharges (Weiss *et al.* 2014).

Discharge teaching is vital to readiness for hospital discharge and requires a vast amount of communication. The content and mode of delivery influence the quality of information or education given to the patient, importantly less is more indicating quality over quantity (Weiss *et al.* 2007). Balaban *et al.* (2008) recommend a formal communication plan, to ensure that everyone is informed of all the details involved in discharge, including written information or instructions for the patient. Nosbusch *et al.* (2011) recommend improvement in continuity of information and patient education, a common path and language between disciplines, so that everyone knows what is done, and what needs to be done.

This concept analysis advances nursing knowledge and the proposed definition can be used in nursing research where readiness for hospital discharge is intended as an outcome measure. It will encourage a unified use of the concept and guide the elaboration of measuring tools. The identification of antecedents, attributes and consequences of readiness for hospital discharge also distinguish it from other concepts. From its definition, readiness for hospital discharge can be developed as an explanatory middle range theory, which conceptually captures readiness to go home from hospital, as felt by the patient. Discharge readiness as experienced by the patient is not equivalent to readiness experienced by the nurse or family members (Anthony & Hudson-Barr 2004, Weiss & Piacentine 2006, Weiss *et al.* 2007) and developing an understanding of patients' perception of readiness, will enhance clinical practice in the discharge process (Weiss *et al.* 2007).

### **1.7 Limitations**

The purpose of this analysis was to define the concept of readiness for hospital discharge, through literature retrieval from key health and social science disciplines. There were limitations. The inclusion of additional disciplines and languages other than English may have broadened the concept. The present analysis was used to investigate a concept that is dynamic and still evolving within the practice of nursing. The antecedents, attributes and consequences could change over time as patients become more educated and prepared to manage their own health issues and as providers improve their services. The use of other methods of concept analysis, such as Rodgers' evolutionary method (Rodgers and Knafl 1993) may have produced different results.

## Conclusion

Readiness for hospital discharge has been identified as a central component of discharge planning and an issue of international relevance in health care. In this chapter the first concept analysis which focused on readiness for hospital discharge is introduced. The objective of this analysis was to provide conceptual clarity and direction for future research and to advance knowledge for professionals by providing an operational definition of readiness for hospital discharge. A better understanding of the phenomenon will assist health professionals to recognise measure and implement interventions where necessary, to ensure patients are ready for discharge from hospital.

By defining the attributes, antecedents and consequences of readiness for hospital discharge through conducting a concept analysis, conceptual clarity is obtained. This clarity is an important aspect of advancing the science related to the concept of readiness for hospital discharge and provides direction for future research on this topic. The conceptual and operational clarity provided by this analysis will inform future decision making and interventions by health care providers in the area of hospital discharge. The concept of readiness for hospital discharge can be used to underpin future research into hospital discharge in different populations and in different cultural contexts and this research paper is available in appendix 5 (Galvin *et al.* 2017). The following chapter presents an empirical integrated literature review using the four attributes of readiness for hospital discharge introduced in this chapter as a guide. These domains are physical stability, adequate support, psychological ability and adequate information and knowledge and this is presented in Chapter Two.

## **Chapter 2- Readiness for hospital discharge**

### **Introduction**

In this chapter an integrative review of the empirical research relevant to readiness for hospital discharge is presented. This critical empirical review will generate the state of current knowledge, identify gaps in the research and give an overview of methodology strengths and weaknesses in the area of readiness for hospital discharge (Wee and Banister 2016). An integrative review was deemed necessary because integrating the in-depth descriptions obtained by qualitative methods with the generalisability of quantitative methods would generate a better picture of the knowledge available on caregiver readiness for the hospital discharge of an older adult (Pace *et al.* 2012).

Shin *et al.* (2011) indicated that caregivers have their own needs as not one single domain of caregiver needs correlate with patient needs. Therefore it was decided to explore caregiver readiness for the hospital discharge of an older adult. The search strategy for this literature review was guided by the four attributes of readiness for hospital discharge provided by Galvin *et al.* (2017).

This search strategy, criteria for inclusion and the findings of the review are presented in this chapter under the following headings: Patient perception of readiness for hospital discharge; Healthcare Providers' practices in getting patients ready for hospital discharge and Caregiver concerns and experiences of hospital discharge.

### **2.1 Search Strategy**

To ensure this is a quality review the search strategy is explained in detail (Wee and Banister 2016). Scholarly peer reviewed journals, published from January 2006 to

March 2019 were searched in CINAHL Plus with Full Text, MEDLINE, PsycINFO, SocINDEX with Full Text and Cochrane databases, using the following search terms and key words: ready OR readiness OR prepared OR prepare OR preparation. This search was combined with the MESH heading Patient Discharge because discharge readiness or discharge preparation were not available as a major concept in CINAHL headings or MESH. This search generated 12,990 hits. Inclusion and exclusion criteria (outlined below) were applied and 95 articles were included in full text screening and 36 studies were reviewed (Appendix 6). In addition, there was no literature review available on readiness for hospital discharge in the Cochrane database.

### **2.1.1 Inclusion & Exclusion Criteria**

Studies included were empirical research articles published in English from January 2006 to March 2019. The papers were then narrowed by major subject headings (Appendix 7). The number of articles included in the initial screening of title and abstract was 1,273. The reference lists of the included articles were hand searched for other relevant articles using the same inclusion and exclusion criteria. The final number of articles included in this review was 36 (Appendix 8).

Pace *et al.* (2012) indicate that appraisal of the methodological quality of included studies is crucial. A search for mixed methods review appraisal tools indicated that the majority of reviews used the Mixed Methods Appraisal Tool (MMAT). This tool allows quality appraisal of quantitative, qualitative and mixed methods studies. Thus, it was deemed an appropriate tool to use in the mixed methods review for the current study. The studies that fit the search criteria were then read and the quality of each study was assessed using the MMAT (Pace *et al.* 2012) (Appendix 9, 10 & 11). All 36 studies satisfied the agenda of the MMAT. The studies were then categorised into themes and the findings are reported chronologically according to these themes.

## **2.2 Patient perception of readiness for hospital discharge**

Patient readiness for discharge has been proven to be a viable and integral part of discharge planning (Weiss *et al.* 2007, Knier *et al.* 2015) and patients who are ready for discharge have better outcomes (Weiss *et al.* 2010, Weiss *et al.* 2011, Coffey & McCarthy 2013, Weiss *et al.* 2014, Weiss *et al.* 2019). Within this section fifteen studies were reviewed the perspective of the patient, eleven of the studies used quantitative methods (Appendix 12) and four used qualitative methods (Appendix 13). All fifteen studies examined patient perception of readiness; three of the studies included some input from caregivers but were primarily focused on the patient. Five of these studies focused on the older adult patient.

The eleven quantitative studies are reviewed first and compared with the findings from the four qualitative studies at the end of this theme. Six of these studies were undertaken in the US, one in Canada, one in Switzerland and one in Turkey. There were two Irish studies, both were quantitative.

In 2006, Weiss and Piacentine developed and validated a Readiness for Hospital Discharge Scale (RHDS). The RHDS is a self reporting instrument with 21 items measuring patient perception of readiness at the time of discharge. It is important to describe this instrument at this stage, as it was the instrument of choice used to measure patient readiness for discharge in seven of the nine quantitative studies reviewed here. There are four subscales to the questionnaire and these are: (1) Personal Status which includes 7 items; (2) Knowledge includes 7 items; (3) Coping Ability includes 3 items; and (4) Expected Support which includes 4 items. The self-report scale was presented as a printed questionnaire. The items were written in question format, and the participant was asked to respond by circling a number from 0 to 10.

Anchor words (e.g. “not at all”, “totally”) were printed at the 0 and 10 poles of the scale to cue the subject to the meaning of the numeric scale. If patients scored  $\geq 7$  they were deemed ready and if they scored  $< 7$  they were not ready for discharge. The scale was designed to be used within four hours of discharge and took 5-10 minutes to complete (Weiss and Piacentine 2006).

During instrument validation Weiss and Piacentine (2006) measured perception from three patient populations (n=356): adult medical/surgical, post-partum mothers and parents of hospitalised children. In addition, patients’ discharge utilisation at 3 weeks was measured hypothesising that patients who are deemed ready by the RHDS prior to hospital discharge would have less post discharge utilisation than those who were deemed not ready, by the same instrument. Patients were also asked to respond to the single dichotomous question: “Are you ready for discharge? Yes or no”. Ninety-six percent indicated yes they were ready for discharge using this question.

Results of the RHDS indicate the mean scores for 19 of the items were  $>7$  (out of 10) indicating that generally patients perceived themselves ready for discharge. The items that scored poorly were energy levels at M6.8 (SD2.4) and stress levels were the lowest at M6.5 (SD3.1). Comparing results, while 96% indicated they were ready for discharge, the 4% who indicated they were not ready scored significantly lower on the RHDS. Results also indicated that on the day of discharge perception of readiness was higher among patients who reported: (i) living with an adult support person, (ii) adequate educational preparation for discharge, and (iii) being more involved in their care coordination. Length of stay in hospital did not improve the patients’ level of readiness. Outcomes at 3 weeks indicated that higher RHDS scores were associated with better coping ability and less likelihood of calling friends and family for support or advice (Weiss and Piacentine 2006).

Subsequently Weiss *et al.* (2007) reported the variables and results specific to the adult medical-surgical portion (n=135) of the larger 2006 study. Findings indicated that 93% of patients reported being ready to go home on the single-item yes/no format question but the researchers reported that 97.3% of this cohort had a call or visit to healthcare provider, emergency room or readmission during the first 3 weeks following discharge. Living alone emerged as the only significant independent predictor of post discharge service utilisation and was associated with a threefold increase in the number of calls to family and friends for support. More effective delivery of discharge information and greater care coordination was associated with greater readiness for discharge (variances of 33% and 44% respectively). Those who perceived themselves to be not ready had more coping difficulties (variance of 16%). This study reported a mean age of 53.4 (SD 15.0) and indicated age as a significant indicator of discharge readiness.

Readiness for discharge of patients < 55 years old was compared with the readiness of four older adult age groups by Bobay *et al.* (2010) using the Quality of Discharge Teaching Scale (QDTS) and the RHDS (Weiss and Piacentine 2006). The questionnaires were completed by medical surgical patients (n= 1449), of whom 1,108 were >55years old and post discharge utilisation was extracted from hospital records after 30 days. When asked the “Are you ready to go home?” dichotomous question, between 95% to 100% of all patients rated themselves as ready to go home, this is a similar result using the dichotomous question to studies by Weiss and Piacentine (2006) and Weiss *et al.* (2007). But the RHDS indicated that between 18% and 24% of older adult patients age  $\geq 55$  years had low levels of readiness (<7 out of 10).

After the age of 55 years, the Knowledge and Expected Support scales are directly associated with perception of readiness. Quality of discharge teaching was associated



with patients feeling ready to go home in the <85 year old patient, this is again similar to findings from Weiss and Piacentine (2006) and Weiss *et al.* (2007). However, discharge teaching did not increase readiness for discharge in the >85year old patient group (Bobay *et al.* 2010).

Nearly 45% of the oldest patients with perceived Coping Ability below 7 were readmitted or used the ED within 30 days. More than 30% of the oldest patients were likely to have post-discharge utilisation if scores on Personal Status and Expected Support were below 7 on the RHDS. When patients >85years old had poor support post discharge, 30% of them were either readmitted, had an unscheduled physician or ED visit (Bobay *et al.* 2010).

In the US, Weiss *et al.* (2011) again examined patient perception of discharge readiness but this time in relation to the impact of nurse staffing levels. Medical/surgical patients completed the QDTS (n=1458) and the RHDS (n=1449) (Weiss and Piacentine 2006). Information was also gathered from unit level staff (nurses), structure administrative data (duty roster) and patients post utilisation ED visits and readmissions within 30 days. Results indicated that at discharge, patients reported a high level of discharge readiness at a mean of 8 out of 10 (SD=1.4), but the readmission rate was 11.9%. An additional 5% had ED visits without admission. Non overtime Registered Nurse (RN) staffing decreased the odds of readmission (one SD increase in RN non-overtime staffing levels i.e. 0.75 hours-per-patient-day was directly associated with a 4.4 percentage point reduction in the probability of readmission). Higher information and knowledge levels among patients were associated with a higher perception of readiness which in turn was associated with less ED visits. This study correlates with the findings of Weiss and Piacentine (2006),

Weiss *et al.* (2007) and Bobay *et al.* (2010) for adult medical surgical patients but does not indicate how many of the participants were older adults.

In Ireland, Coffey and McCarthy (2013) assessed the perception of older adults' readiness for discharge. Data were collected from a convenience sample of older adult patients (n=335) who were >65yrs, at discharge and at six weeks post discharge using a researcher developed questionnaire and the RHDS (Weiss and Piacentine 2006). Sixty two percent of the patients were aged over 75 years, and 33.7% were older than 80 years. At discharge the dichotomous question "are you ready to go home? Yes/no" indicated a 93.7% affirmative rate which correlates with studies by Weiss and Piacentine (2006), Weiss *et al.* (2007) and Bobay *et al.* (2010). The RHDS indicated that patients were ready for discharge with a mean of 7.31 (SD 1.18). Patients over 80 years experienced lower levels of perceived readiness at 6.83. This age group also scored lower in knowledge (median 6.67) and coping ability (median 7.33). Lower knowledge amongst older patients was also discovered by Bobay *et al.* (2010).

At discharge, <20% of patients had referrals to community supports other than the PHN or GP and over 80% reported that they did not have informal support in place. Results at 6 weeks revealed that GP services were used by 90% and PHN visits increased. Use of informal support (family and friends) had increased, (4-12%) overall. In this study, less time in hospital increased informal and formal support after discharge. Female respondents and those >80 years were statistically more likely to be in receipt of informal support with Activities of Daily Living (ADLs). Use of PHN and home help services significantly increased with the older age group. Overall, 25% of respondents were readmitted and those >80 years, who were initially an emergency admission, were almost four times more likely to be readmitted within six weeks. A lower mean readiness in the subscale 'personal status' existed in respondents who

were readmitted within 6 weeks post-discharge (mean 7.4,SD 1.8) compared with those who were not readmitted (Coffey and McCarthy 2013).

In the second Irish study, Brent and Coffey (2013) assessed orthopaedic patients' perception of their readiness for discharge. Patients >75 years (n=50) were assessed with the RHDS (Weiss and Piacentine 2006) and demographic variables. The single item dichotomous question "are you ready for discharge" (yes/no) indicated an 88% affirmative rate which is lower than studies by (Weiss and Piacentine 2006, Weiss *et al.* 2007, Bobay *et al.* 2010, Coffey and McCarthy 2013), but the RHDS also indicated readiness was low with physical and emotional readiness the lowest variable at 6.68 (SD 1.1). Perceived readiness scores for expected support were 7.99 (0.27) and those living alone had lower scores at 6.09 (SD 1.08) Coping scored 7.01 (SD 0.32) and the knowledge subscale had a low score of 6.29 (SD 1.04). Results demonstrated that there was little difference between gender but readiness scores decreased overall as age increased and those who lived with family had a higher perception of readiness in all RHDS (Weiss and Piacentine 2006) subscales. This study had a small homogenous cohort but the results do compare to studies by Bobay *et al.* (2010) and Coffey and McCarthy (2013). Other studies found living alone was also a significant predictor of post discharge support (Weiss *et al.* 2007, Bobay *et al.* 2010).

Patients' perception of readiness was explored and compared with nurses' perception of readiness by Weiss *et al.* (2014) in the U.S. The study design was prospective and longitudinal with a final study sample of 54 discharge nurses and 254 adult medical surgical patients. Nurses and patients independently completed the survey, nurses completed the RN-RHDS-SF<sup>1</sup> and patients completed the PT-RHDS-SF<sup>2</sup>. Post

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<sup>1</sup> RN-RHDS-SF<sup>1</sup> ( Nurse - Readiness for Hospital Discharge Scale – Short Form) and PT-RHDS-SF<sup>2</sup> ( Patient - Readiness for Hospital Discharge Scale – Short Form) both developed by Weiss *et al.* (2014).

discharge ED visits and readmissions were obtained from electronic records. Results indicated that 15% of patients rated themselves as having low readiness compared to nurses' rating 12.6% of patients having low readiness. Patients rated physical readiness ( $p=.006$ ) and energy levels ( $p<.001$ ) lower than nurses and nurses rated the need of physical help at home higher than patients ( $p=.01$ ). When nurses assessed patients to have low discharge readiness there was a six to nine fold increase in readmission. For every one point increase in the RN-RHDS-SF<sup>1</sup> there was a 39-47% reduction in readmission. Including the patient perspective in this case did not add to explanations of readmission beyond that of the nurses' explanation (Weiss *et al.* 2014). This is the first nurse assessment of patient readiness used and had positive results. It could be tested on other cohorts such as older adults.

In the US Schmocker *et al.* (2015) sought to determine a relationship between patient perception of readiness for discharge and their 30 day readmission rates. To determine readiness for discharge patients ( $n=318$ ) were asked: "Did you feel ready for discharge?" This question had 5 possible responses: very poor, poor, fair, good, and very good. Those who responded with the highest response (very good) were deemed ready for discharge. Patients with all other responses were combined and deemed less ready for discharge. The 30 day readmission rate for patients who were less ready for discharge was 18.2% compared to 11.4% for those who perceived themselves as ready (Schmocker *et al.* 2015) indicating that those who are less ready for discharge have a 7% higher rate of admission than those who are more ready for discharge.

In Canada, Lau *et al.* (2016) conducted a study to assess patients' perception of readiness and examine predictors of readmission. Patients ( $n= 495$ ) were asked "How ready do you feel to be discharged from hospital?" on an 11-point Likert scale, with 0 as "Not ready" and as 10 "Ready.". Results indicated that 77% of patients scored their

perception of readiness as  $\geq 7$  which the researchers declared as indicative of ready. Among the 23% of patients who were not ready the median readiness score was 4. At 30 days, 16% were readmitted, 3% had died and 26% had attended the ED. Age was a significant predictor of poor discharge readiness with younger adults in this study being less ready correlating with Weiss *et al.* (2006). There were no difference in outcomes between those who were ready versus those who were not ready in the number of readmissions, ED visits or death in this study (Lau *et al.* 2016).

In Turkey variables that affect patients' perceptions of their readiness for discharge and the impact on patient outcomes were measured (Kaya *et al.* 2018). Questionnaires comprising of the RHDS (Weiss and Piacentine 2006), demographic questions and a 30 day occurrence of any of the following three: unplanned readmission to the hospital; emergency department visits; and death. This was a 1-year prospective cohort study on a sample of 1,601 patients >18years. Results from the RHDS indicated that 40% of patents were not ready for discharge. This is the highest average of unready patients uncovered by any of the quantitative studies in this section. The average age of unready patients was 62.3 (17.2SD) years versus the average age of ready patients at 53.1 (18.4 SD), indicating that unready patients were on average almost 10 years older than their counterparts. This was also found to be the case in studies by Bobay *et al.* (2010) and Coffey and McCarthy (2013). However, Kaya *et al.* (2018) indicate that variables such as being single, female, having a low education level, living alone, not having someone to help at home and utilising the intensive care unit before discharge decreased readiness scores 1-2 fold when age was increased by 1 year.

Patients who were not ready for discharge also had higher comorbidity scores. Examining the outcomes, unplanned readmissions were significant at 48 unready patients versus 40 ready patients. The risk of death for unready patients was

significantly higher at 81 versus 71. The effect of personal status on unplanned readmissions was significant and the effects of personal status and coping ability on death within 30 days after discharge were also significant (Kaya *et al.* 2018).

The final quantitative study in this section was a recent study in Switzerland by Mabire *et al.* (2019) which aimed to explore the associations between unit, nurse and patient characteristics with patient readiness for hospital discharge. A total of 1,833 registered nurses and 1,755 patients from 123 surgical, medical and mixed units in 23 Swiss acute care hospitals were included in the analyses. The outcome variable of patient readiness for hospital discharge was evaluated by a single item: “Did you perceive that the institution prepared you for the time after the treatment was finished”? The answer options ranged from 1 (not prepared) to 5 (fully prepared) on a Likert scale, with additional an answer option “I don’t know”. An answer of 4 or 5 indicated the patient felt prepared. Results indicate that 62% of patients declared themselves ready indicating 38% were not ready which is a similar finding to Kaya *et al.* (2018). Medical and larger units were significantly associated with lower levels of readiness while units with more experienced nurses were significantly associated with higher patient readiness. The authors hypothesised that experienced nurses were more effective coordinators of discharge plans than novices and view discharge preparation as more of a priority.

The four qualitative studies in this section are now reviewed and will be compared to the findings from the quantitative findings. In Canada Neiterman *et al.* (2015) explored how high risk older patients (n=17, >70 years) experience transitions from hospital to home. Results indicated post discharge care was often presented in a disorganised way and that adaptation to daily life and daily activities was a real challenge for patients who said the transition was overwhelming, chaotic and confusing. Those who lived

alone often reported being depressed and had challenges such as no food in the fridge. Those who had the support of family members were more successful in adapting to the transition which echoes findings from the quantitative studies reviewed above (Weiss and Piacentine 2006, Weiss *et al.* 2007, Bobay *et al.* 2010, Brent and Coffey 2013). Lack of familiarity with community services was emotionally and physically draining and this was also a problem discovered by Coffey and McCarthy (2013). Post discharge medication management was difficult because of changes in medications. Patients reported being happy with their caregivers and preferred to rely on them to coordinate care but caregivers also felt the transition was overwhelming, chaotic and confusing. Caregivers reported that they lacked physical skills and sufficient knowledge. They felt the news about discharge came too fast before they had a chance to prepare the home for the patient (Neiterman *et al.* 2015).

In the Netherlands, Satink *et al.* (2015) explored the readiness of stroke patients to manage self-care post discharge. This qualitative study indicates that self-management was difficult for the stroke survivor. The stroke survivors stated they could not have managed without their relatives from whom they required help to cope with changes in their roles and daily lives, which again compares to findings from many studies already reviewed (Weiss and Piacentine 2006, Weiss *et al.* 2007, Bobay *et al.* 2010, Brent and Coffey 2013, Neiterman *et al.* 2015). Many of the participants felt neglected in their needs because therapies were discontinued too early. Patients indicated that they required more support in the immediate discharge period, especially in the area of managing daily care. In this study all the stroke patients had received some form of rehabilitation post the acute hospitalisation period.

Recently, in Australia Allen *et al.* (2018) conducted a qualitative study aiming to understand how older people and their caregivers experience discharge from acute and

rehabilitative care. Using thematic analysis six themes were identified: (i) Needing to become independent; (ii) Supportive relationships with caregivers; (iii) Caring relationships with health-care practitioners; (iv) Seeking information; (v) Discussing and negotiating the transitional care plan; (vi) Learning to self-care. All patient participants described the need to become independent. All patients were >70years old and continued to require support from caregivers at home. Most participants agreed that family support was crucial to preventing re-admission to hospital reiterating findings from almost all of the other studies in this theme (Weiss and Piacentine 2006, Weiss *et al.* 2007, Bobay *et al.* 2010, Brent and Coffey 2013, Neiterman *et al.* 2015, Satink *et al.* 2015). According to two participants, family and friends were asked to collect the person on the evening of discharge. They noted that this would have resulted in discharge home alone, with no food in the house. These caregivers perceived that this was uncaring, unsafe, and an uncoordinated discharge.

If Health Care Providers (HCPs) were polite then the patients felt cared for and safe. When the patient was too unwell to seek information about medication changes, their caregivers wanted to know this information on their behalf. Most participants expected medical practitioners to share this information with them during the hospital admission, although this did not always occur. However, those who received care from the rehabilitation ward noted they were well informed of their medical diagnoses and changes in their medications (Allen *et al.* 2018).

Mitchell *et al.* (2018) carried out a large qualitative study to identify the care transition outcomes most important to caregivers and patients. Three themes were identified as integral to discharge transitions: (i) feeling cared for and cared about by medical providers, (ii) having unambiguous accountability on the part of the health care system and (iii) feeling prepared and capable of executing the care plan upon discharge.



Participants need HCP's to use compassionate, empathic language and gestures when communicating and they require the HCP's to anticipate patient and caregiver needs at home after discharge. Participants also wish to engage with the HCP's in collaborative discharge planning.

Unfortunately caregivers reported that health professionals often devised discharge plans that required caregiver cooperation without eliciting caregiver input. And caregivers emphasised the importance of engaging with them in discharge planning. Caregivers described how the patient declined offers for a visiting nurse or home health aide to assist with personal care at home but the family did indeed need these additional supports and without it, the caregiver was left with inadequate resources to manage safely alone (Mitchell *et al.* 2018).

## **Summary**

Out of the nine quantitative studies reviewed in this section, eight measured patient outcomes between 3 and 6 weeks post hospital discharge. Seven of these eight studies agree that unready patients have poorer outcomes after discharge with between 20% to 40% of patients declared not ready at the time of discharge (Weiss and Piacentine 2006, Weiss *et al.* 2007, Bobay *et al.* 2010, Weiss *et al.* 2011, Coffey and McCarthy 2013, Schmocker *et al.* 2015, Kaya *et al.* 2018, Mitchell *et al.* 2018) and one study that declares no significance between unready patients and poorer outcomes used a different less informative instrument to measure readiness (Lau *et al.* 2016).

Significant factors uncovered here that cause patients to be unready and increase post discharge utilisation are: living alone and poor support (Weiss and Piacentine 2006, Weiss *et al.* 2007, Bobay *et al.* 2010, Brent and Coffey 2013); age as older patients are less ready (Bobay *et al.* 2010, Brent and Coffey 2013, Coffey and McCarthy 2013,

Kaya *et al.* 2018); education or knowledge as those who declared adequate educational preparation were more likely to be ready than those who did not (Weiss and Piacentine 2006, Weiss *et al.* 2007, Bobay *et al.* 2010, Weiss *et al.* 2011, Brent and Coffey 2013, Coffey and McCarthy 2013, Kaya *et al.* 2018), although, Bobay *et al.* (2010) discovered that education did not increase readiness in the over 85 year and older cohort as did Coffey and McCarthy (2013). Reasons for this may indicate that older patients are perhaps frailer and unable to concentrate. Whatever the reasons the older old have different requirements to their younger counterparts.

Patient readiness for discharge has been shown to be significant as those who are not ready have poorer post discharge outcomes such as readmission (Bobay *et al.* 2010, Coffey and McCarthy 2013, Schmocker *et al.* 2015, Kaya *et al.* 2018). Patients who are not ready also have outcomes such as increased use of informal supports as in family members assisting in areas including daily care, medication and transport (Bobay *et al.* 2010, Coffey and McCarthy 2013).

Post discharge support is the most important factor in patient perception of readiness for discharge as well as preventing poor outcomes post discharge, with living alone the most significant demographic affecting patient discharge readiness (Weiss and Piacentine 2006, Weiss *et al.* 2007, Bobay *et al.* 2010, Brent and Coffey 2013).

### **2.3 Healthcare Providers' practices in getting patients ready for hospital discharge**

Healthcare providers (HCP) are an important component of the discharge process therefore studies examining what the HCP does to get the patient ready for hospital discharge were included in this review. Within this theme ten studies were reviewed, six were quantitative, two were qualitative and there were two mixed methods studies.

Four studies were from the USA, two from Taiwan and four were European studies which included one Irish study. Five studies focused on documentation and referrals and five studies focused on discharge planning programs (Appendix 14).

The first qualitative study aimed to examine how nurses prepare patients for discharge home during the period of hospitalisation (Foust 2007). The sample consisted of nurses (n=8) of varied levels of education looking after female patients (n=7) post gynaecological surgery. The findings indicated that getting patients ready for discharge was the focus of discharge planning. Nurses integrated many components of discharge planning into their daily practice and the most commonly expressed criterion by nurses was physical state. Nurses regularly assessed patients' emotional response to hysterectomy and they also assessed their patients understanding of discharge plans and instructions. A significant amount of teaching took place as they cared for patients; it was not a separate activity but the richness of discharge teaching and planning was missing from the notes therefore a gap between observed and documented discharge planning efforts existed (Foust 2007).

Exploring the management of the older person post discharge from the emergency department (ED) from a healthcare services perspective was the aim of an Irish study by Dunnion and Kelly (2008). Findings indicated that in this study 74% of PHNs were never notified of older patient discharges from the emergency department. In addition, 40% of ED doctors thought the level of referral was good or very good; this contrasted sharply with GP's perception where 59.4 % declared referrals as unsatisfactory. Furthermore, 47% of hospital nurses also said that the referral level was unsatisfactory. 96% of PHNs and 93% of GPs agreed there was a need to increase and improve the level of referral between the emergency department and the primary care sector and GP's declare that referrals that they do receive are often illegible. All agreed that a

standardised computerised discharge form that could be printed out and sent out to different members of primary care team by post or email was necessary (Dunnion and Kelly 2008).

In the UK, Connolly *et al.* (2010) examined current discharge preparation in an acute hospital. A questionnaire designed for the purpose by Connolly *et al.* (2009) was used with all staff (n=455) involved; nurses, midwives, doctors, dieticians, physiotherapists, occupational therapists, social workers and pharmacists. Findings indicated that documentation was perceived to be satisfactory by 70% of respondents which contrasts with findings from Dunnion and Kelly (2008) where approximately 60% declare referral documentation as unsatisfactory. 75% of practitioners agreed that waiting for one part of the discharge plan to be completed delayed their input while 72% agreed that moving patients from one ward to another could delay discharge. Where staffing levels were perceived to be adequate, discharge was noted to run relatively smoothly but opinion was split on the question of whether patients and caregivers were involved in all stages of discharge (Connolly *et al.* 2010).

The frequency of communication between nurses and caregivers documented in the nursing notes was studied by Oliveira *et al.* (2011). This study was a quantitative descriptive, exploratory, retrospective collection of nursing data from 816 patient's notes over 907 admissions. Findings indicated that 56.9% of patient records have no documented communication on discharge teaching of the informal or family caregiver. Consequently 92% of caregivers showed deficient knowledge and deficient skill in caring for patients (Oliveira *et al.* 2011).

Hesselink *et al.* (2012) conducted a qualitative study of patient handovers to the primary care sector, to explore barriers and facilitators to patient centred care in the

hospital discharge process. This was a large study involving five European countries. Four themes emerged: (1) Health provider prioritisation of discharge consultations; (2) Decision-making within the discharge process; (3) Care provider anticipation of patient-specific needs and preferences; and (4) Organisational factors. The main points within these themes were declaration of lack of time as a barrier to discharge consultations which meant consultations took place at times that were convenient for physicians but not for family members, this prevented them from being adequately informed. There was an absence of a standard discharge consultation process which meant that discharge information given irregularly, consequently, patients, especially older people, are often unaware of the importance of the information provided. Within decision making some patients felt they were included and some felt they had no voice at all and sudden and abrupt discharges overwhelmed patients. Even though nurses are aware of patients emotional needs during hospital discharge patients and family members mentioned that there was little awareness of the patient's emotional status by care providers, Care providers are aware that patients need to be prepared for discharge but hospital however, community nurses, GPs and patients indicated that patients often receive insufficient instructions concerning their follow-up (Hesselink *et al.* 2012).

Organisational factors that contribute to issues in the area of hospital discharge are the structure of doctors and nurses shifts and patients were advised to contact their GP if they had problems post discharge, but GP's did not have up to date information about the patients' recent hospital admission. Identification of a doctor or nurse who was the main care provider during the hospital stay would help if difficulties or questions arose at home after discharge. Early discharges are caused by the pressure of financial

drivers and lack of hospital beds. Late evening or weekend discharges were problematic due to out of office hours of GP's and pharmacies (Hesselink *et al.* 2012).

The next five studies conducted discharge planning programs these studies are compared to the previous five studies at the end of this section. Shyu *et al.* (2008) aimed to measure the outcomes of a discharge planning program on caregivers of older (> 65years) stroke patients. Data were collected by the research nurse who as step one of the program visited the patient and caregiver (n=72 dyads) prior to discharge. The program also included a follow up telephone call within the first week and two home visits within a month. Caregiver preparation in both groups was moderate prior to the intervention (intervention group M=11.03, control group M=11.10, out of a total of 15). After three days both groups improved, but caregivers in the intervention group were slightly more improved (intervention group M=12.75, control group M=11.76, out of a total of 15). Caregiver self-evaluation using the Preparedness for Caregiving scale (Archbold *et al.* 1990) indicated both groups as moderately ready within the first three days (intervention group M=23.36, control group M=22.45, out of a total of 35), but after the intervention (prior to discharge), the intervention group self-evaluated their preparation as significantly improved (M=26.00 out of a total of 35) while the control group did not improve (M=23.13 out of a total of 35). Caregiver needs measured by the Caregiver Discharge needs Satisfaction Scale (Shyu 2000), indicated a significant improvement in both groups one month after discharge but a significantly higher satisfaction score was noted in the intervention group (intervention group M=3.55, control group M=2.09, out of a total of M=4).

A follow up study by Shyu *et al.* (2010), explored the long term effects of the post discharge planning program on the two study groups from Shyu *et al.* (2008) study. Results indicated that during the first six months, 9 subjects in the experimental group

and 16 in the control group were institutionalised but institutionalisation was significantly lower in months 6-12 in the intervention group with 0 patients admitted to long term care in comparison to the control group where 6 patients were admitted to long term care. This indicates the success of their discharge planning program on enhancing caregiver preparation one year later.

In the USA Saleh *et al.* (2012), conducted a randomised controlled trial (RCT) targeted at the older adult ( $n = 292$ ,  $>65$  years). They used a post care transition program (PDCT) which consisted of a comprehensive discharge preparation checklist, followed by three home visits. Outcomes were measured by the assessment of self-management skills and abilities using the Coleman's Care Transitions Measure Survey (Coleman et al 2002 & 2004), readmission rates and a cost-benefit analysis. The PDCT enhanced participants degree of understanding in a number of areas such as how to manage their health ( $P = .003$ ), understanding the warning symptoms and signs patients should watch for ( $P = .004$ ), understanding the written plan ( $P = .01$ ), confidence to manage their health ( $P = .03$ ), and being able to do the things that they need to take care of their health ( $P = .03$ ). Furthermore, participants in the PDCT had a significantly better understanding of the purpose of taking their medications than the control group ( $P = .008$ ), whose understanding slightly declined between the initial and repeated evaluation.

The 30-day readmission rate in the intervention group was slightly higher than in the control group (8.6% vs. 7.2%) but readmission analysis revealed that individuals in the control group were more likely to be readmitted (58.2% vs. 48.2%) in the 31 to 90 day period indicating the intervention as successful in the second 30 days and beyond. The cost benefit analysis indicated for every \$1 spent on the program a saving of \$1.09 was realised from reduced readmission (Saleh *et al.* 2012).

In the US Knier *et al.* (2015) evaluated an inter-professional discharge planning program. A quantitative survey design was used with rehabilitation patients (pre n=36, post n=31). The Discharge Process Acute Rehabilitation Transition (DePART) tool was tailor made to the individual. The program focused on improvement in discharge teaching, reduced variability in discharge planning and focused on people's individual needs by visiting patients at home identifying a primary caregiver and developing a patient centred checklist. Patients were evaluated before and 3 months after the program using the RHDS and the QDTS (Weiss and Piacentine 2006). The RHDS indicated that perceived support improved (pre M 8.59, SD1.53 and post M9.24, SD.94) and the QDTS showed significant improvements in discharge teaching (pre M7.96, SD1.43, post M8.8, SD1.14) (Knier *et al.* 2015).

A recent study in the US aimed to determine whether implementation of structured discharge readiness assessments during discharge preparation could reduce return to the hospital following discharge (Weiss 2019). An RCT using the Readiness Evaluation and Discharge Intervention (READI) was conducted within 33 hospitals. Data were collected from 1 intervention unit and 1 control unit in each participating hospital. Eligible patients were adults (aged  $\geq 18$  years) discharged to home following an inpatient admission. A total of 144,868 patients with a mean age of 59.6 [SD17.5] years took part in the study.

There were 3 variations of the discharge readiness assessment; The READI1 protocol required the discharging nurse to complete an assessment of patient readiness on the day of hospital discharge using the Readiness for Hospital Discharge Scale nurse form (RN-RHDS) and the nurses were instructed to use their best judgment to guide actions in completing their patients' preparation for discharge; The READI2 protocol added the patient self-assessment version of the RHDS (PT-RHDS), which was reviewed by



the discharging nurse immediately before completing the RN-RHDS, so that the patient's perspective would inform the nurse's assessment and action; The READI3 protocol assessed the RN-RHDS and the PT-RHDS and additionally instructed nurses that a score lower than 7 of 10 on the RN-RHDS or PT-RHDS indicates low readiness and required documentation of actions taken to increase patient readiness for discharge (Weiss 2019).

Results indicated that mean scores increased across the protocol phases: RN-RHDS increased from 8.14 (out of 10) during READI1 to 8.20 with READI2 and to 8.60 with READI3; PT-RHDS increased from 8.42 during READI2 to 8.64 with READI3. There was a reduction in readmission of 1.38% with READI1, and 3.05% with READI2. ED rates decreased with all protocols; READI1 by 2.33%; READI2 by 1.32%; and READI3 by 1.43%. This sample was restricted to medical-surgical units from hospitals that had achieved Magnet designation for nursing excellence indicating that findings may differ in hospitals with different levels of care quality (Weiss 2019).

## **Summary**

In summary ten studies focusing on the practices of the healthcare provider in preparing the patient for discharge were reviewed. Studies that focused on documentation regarding preparation for discharge indicated that nursing notes were inadequate (Foust 2007, Oliveira *et al.* 2011) and there is very little documentation that indicates caregivers are included in preparations (Connolly *et al.* 2010, Oliveira *et al.* 2011, Knier *et al.* 2015). Support is one of the main attributes for patient readiness for hospital discharge (Galvin *et al.* 2017) with caregivers being the main support but the GP and PHN are the most common community supports post discharge

and this review indicates post discharge supports are not routinely offered and referrals are poor (Dunnion and Kelly 2008, Connolly *et al.* 2010).

Comparing the five discharge planning programs reviewed here discharge planning programs reduced readmission rates, reduced visits to the ED and created financial savings (Saleh *et al.* 2012, Weiss 2019). Three of these programs focused on the >65years and found that older patients relied on their caregivers throughout the transition to home (Shyu *et al.* 2008, Shyu *et al.* 2010) and discharge planning programs assisted the caregivers to prepare for discharge decreasing institutionalisation up to one year later.

However these programs also indicate that caregivers who do not receive specific targeted support are overwhelmed (Knier *et al.* 2015). Tailored discharge planning programs have a positive effect on patient readiness for discharge but they are not routinely practiced. In addition, evidence suggests that HCP's are unsure whether caregivers are included in the discharge process and caregivers largely showed deficient knowledge in caregiving practices (Connolly *et al.* 2010, Oliveira *et al.* 2011, Hesselink *et al.* 2012, Knier *et al.* 2015).

#### **2.4 Caregiver concerns and experiences of hospital discharge**

An integral part of patient readiness for hospital discharge is their support system (Galvin *et al.* 2017). Evidence suggests that caregivers are important to the patient in order to feel ready to go home from hospital (Shyu *et al.* 2008, Coffey and McCarthy 2013). There were eleven studies in this theme, nine used qualitative methods, one used quantitative and one was a mixed methods study. Five of the studies were undertaken in Australia, three in the US, one in Sweden, one in Norway and one in

Denmark. All of the patients had home as a final destination but one of the studies explored going from rehabilitation to home (Appendix 15).

In Australia, the problems experienced by caregivers after hospital discharge were explored by Boughton and Halliday (2009). Both patients (n=7) and caregivers (n=7) were interviewed separately and no attempt was made to compare caregiver data with patient data but a descriptive qualitative analysis was conducted to develop an overall picture. The interviews took place in the patient's residence 5 days after discharge. Three themes were uncovered: (i) Uncertainty through lack of preparation for discharge; (ii) Uncertainty through lack of information and (iii) Uncertainty of being at home. Results indicated that all the caregivers in this study were uncertain and would have liked someone to tell them that what they were doing was right. They would have been greatly relieved to have contact with a health professional as a matter of routine. They indicated that their chemist and GP were the main sources of help and a return to the hospital was sometimes necessary. All caregivers admitted to concern and apprehension and indicated that if they had good quality information they would not have been so concerned. Comparing this to the patients in the same study, patients were also uncertain and they stated they did not receive enough information either (Boughton and Halliday 2009).

In Sweden, Rydeman and Törnkvist (2010) examined how caregivers of older persons experienced the discharge process. Interviews with caregivers (n=12) looking after older patients (>65 years) were carried out at home 4-6 weeks after discharge from the acute hospital. Three significant themes or preparation areas were identified: (i) Caring issues; (ii) Activities of daily living and (iii) Where to turn. If these issues or needs were satisfied, caregivers felt prepared for life at home at discharge. Participants

articulated that when they had adequate information and time to make arrangements they felt prepared for life at home after discharge (Rydeman and Törnkvist 2010).

Returning to Australia, Fitzgerald *et al.* (2011) aimed to understand caregivers' experience of hospital discharge. Interviews with caregivers (n= 25) of patients diagnosed with dementia were conducted approximately 2 months after discharge. Three key themes emerged: (i) Insufficient communication; (ii) Inadequate preparation for discharge and (iii) undervaluing the family carer as a resource. Findings indicated that caregivers were under the impression that staff would prepare the patient for discharge by getting them to assist in personal care but this did not occur. Caregivers perceived their issues were not heard and the hospital experience left many feeling unimportant and frustrated. Findings also indicated a lack of co-ordination with support services. Notification of discharge was often by a chance meeting when visiting the patient and some caregivers got no notification of discharge at all. Discharge information was provided randomly and caregivers' perceived plans to be made without any input from them. None of the caregivers in this study were provided with any written discharge information (Fitzgerald *et al.* 2011).

Remaining in Australia, Perry and Middleton (2011) aimed to identify caregiver needs of stroke caregiving after hospital discharge. They carried out a mixed methods study with caregivers (n=32) using several instruments (Appendix 15) between 1 and 3 months post discharge. Findings indicated 22.1% of caregivers had an absence of knowledge about looking after a person with stroke after hospital discharge. Results also indicated that restricted social lives, tiredness, distress about the stroke survivors' state and difficulties getting information to prevent further stroke were issues for 37% of the caregivers interviewed. Four themes were uncovered in the qualitative section: (i) Stroke as a family affair; (ii) Changed personality, roles and relationships; (iii)

Uncertainty and anxiety and (iv) Conflicted attitudes which meant some caregivers had a love–hate relationship with the caregiving situation (Perry and Middleton 2011).

Occupational therapists, Gustafsson and Bootle (2013) aimed to explore the discharge transition experience from the perspective of caregivers (n=5) looking after patients with stroke. Interviews took place approximately 1 month after discharge. Findings from the perspective of the caregiver yielded three themes: (i) the purpose of rehab; (ii) Life is different now and; (iii) Looking to the future. In common to findings in Fitzgerald *et al.* (2011) caregivers were disappointed that routine personal care activities were done by nursing staff during hospitalisation rather than promoting the independence of the patient. Patients indicated that assistance received from caregivers was necessary and positive but caregivers were overwhelmed and worried about their own health and the ability to sustain this level of caregiving into the future. Those caregivers who got information on community supports were happy with the service but some got no information and were upset because they needed that extra support. Caregivers specified the family conference as crucial for communication and discussion of all issues prior to discharge (Gustafsson and Bootle 2013).

In the US, Young *et al.* (2014) aimed to understand the needs of spousal caregivers of stroke survivors, during transition from rehabilitation to home. Initial interviews were held with caregivers (n=14) within three weeks of discharge and the second three to six months later. Findings indicated the discharge home process as very difficult, sometimes even traumatic for caregivers and caregivers reported feeling pressured to take the patient home despite feeling unprepared. As a result caregivers were overwhelmed. Several caregivers had physical, mental or emotional problems that made caregiving more challenging. The researchers recommended that caregivers should have their physical health assessed and the caregiver along with the patient

should have their support needs reviewed on a regular basis. The researchers also noted that no instruments existed to assess the capacity of caregivers to provide care at home, prior to discharge of the patient (Young *et al.* 2014).

In Denmark, Ågård *et al.* (2015) explored the challenges facing spouses of Intensive Care Unit (ICU) patients post discharge. Interviews were held at 3 months (n=18 spouses & n=18 patients) and 12 months (n=16 spouses & n=17 patients). Most spouses reported that they were in good health themselves but some reported problems such as pain, arthritis and social problems. Some struggled to manage and would have appreciated more formal support. Only one spouse was offered social support, the rest relied on family and friends. Spouses relied on their GP but the GP did not have a co-ordinating role during convalescence. Huge uncertainty was common. Balancing the needs of the patient, family, children and employment was stressful. No formal training was given and most learned by doing. Caregivers described rewarding feelings if they found solutions to the many challenges. The researchers recommend that the role of society in supporting informal caregivers after discharge needs further research (Ågård *et al.* 2015).

In the US, Coleman & Roman (2015) used focus groups (n=4) to explore caregiver experience during the discharge transition from hospital. Interviews took place approximately 3 months after discharge. Findings indicated that health needs of caregivers were different to the patient and caregivers wanted to be included in decision making and to be more visible. However, many caregivers sensed that their presence triggered annoyance amongst healthcare professionals. They expressed the need for a single trusted professional they could contact when they need help. After discharge caregivers were not confident in taking on roles that were often imposed on them without warning and they were overwhelmed by medication management. The

researchers suggest that offering support to caregivers could be a significant step forward and that caregiver readiness for the patients discharge is rarely ascertained (Coleman and Roman 2015).

Toye *et al.* (2016) investigated the extent to which caregivers of older people are prepared for discharge. This was an RCT where the intervention comprised usual discharge care plus the Further Enabling Care at Home program with caregivers of patients  $\geq 70$  years (Intervention group  $n=77$  vs. Control group  $n=86$ ). The program was delivered by a specially trained nurse over the telephone and included: support to facilitate understanding of the patient's discharge letter; caregiver support needs assessment; caregiver prioritisation of urgent needs and collaborative guidance from the nurse, regarding accessing supports over 3 time points, 9 days, 24 days and 40 days after discharge. In this study caregivers declined participation because they were too busy or overwhelmed. Results indicated that preparedness to care improved significantly in the intervention group and caregivers in the intervention group had a decrease in caregiver distress and strain indicating caregiver preparation improves outcomes (Toye *et al.* 2016).

A Norwegian study (Rustad *et al.* 2017) aimed to understand how caregivers ( $n=9$ ) experience the care transition of an older relative from hospital. Interviews took place approximately 2 weeks post discharge. The over-arching theme was that caregivers balance multiple tasks during older relatives' care transition. One subtheme indicated that caregivers strive to fulfil informational needs during the care transition. They need to obtain information about how the healthcare system works and in turn provide information to healthcare services and their older relative. Insufficient information and vast responsibilities lead to unnecessary concerns and worries. Caregivers were frustrated about whether obtaining information should be the caregivers' initiative or

if healthcare staff had an obligation to make contact. Some caregivers received information about treatment and care from the older patient themselves but some, because of their relatives' health condition, found that the information they were given was incomplete. Subtheme two indicates that caregivers take responsibility for the older relative during the care transition and described the importance of helping their older relative to regain a level of self-management. They shared the responsibility for their older relative with other family members and tried to accommodate changes in their own daily lives (Rustad *et al.* 2017).

Schwartz *et al.* (2019) explored the home caregiving experiences of caregivers (n=13) of cancer patients in the two weeks following a hospital discharge. Three themes emerged: (i) Caregiver and patient wellness are connected; (ii) Caregivers struggle with control issues and (iii) Challenges in communication with health professionals (Schwartz *et al.* 2019). Findings highlight that there are specific issues for caregivers of cancer patients but that these caregivers also deal with regular caregiving issues and some of the same hospital discharge issues such as poor communication and lack of information.

## **Summary**

In summary, even though provision of discharge information has been the mainstay of discharge preparation, throughout this theme both qualitative and quantitative studies indicate that issues with communication and lack of knowledge after hospital discharge are the main issues for caregivers (Boughton and Halliday 2009, Rydeman and Törnkvist 2010, Fitzgerald *et al.* 2011, Perry and Middleton 2011, Young *et al.* 2014, Ågård *et al.* 2015, Coleman and Roman 2015, Schwartz *et al.* 2019). Research by occupational therapists reiterated the research by nurses indicating information or



lack thereof as the common thread (Gustafsson and Bootle 2013), as did a study in a faculty of medicine in the US (Coleman and Roman 2015). Discharging patients from rehabilitation to home, the results were similar to those patients discharged from the acute setting to home, reiterating lack of information and feelings of uncertainty among caregivers (Young *et al.* 2014). This problem was common in Australia, the US and Europe indicating this is an International issue.

Approximately half the studies focused on caregivers of older adult patients and they also identified lack of knowledge and poor communication between the HCP and caregivers (Rydeman and Törnkvist 2010, Gustafsson and Bootle 2013, Coleman and Roman 2015, Toye *et al.* 2016). Feeling overwhelmed and undervalued was commonly expressed by caregivers (Fitzgerald *et al.* 2011, Ågård *et al.* 2015, Coleman and Roman 2015) and a discharge program targeted at caregiver preparation indicated that those who received the program coped significantly better (Toye *et al.* 2016).

There were no studies on older adult caregiver concerns or experiences from an Irish or English perspective available at this point in time. The timing of data collection also varied at anything from 5 days to 3 months and no study has collected data within 24 hours of discharge.

## **Conclusion to literature review**

Chapter one developed a conceptual definition of patient readiness for hospital discharge: Readiness for hospital discharge is both a state and a process. It is characterised by the person/patient having: physical stability including functional ability and competence to manage self-care at home; adequate support to cope with multiple demands after leaving the hospital; psychological ability, where the patient has become confident enough to manage the transition or process; and has adequate

information and knowledge to respond to common problems during the post hospitalisation period (Galvin *et al.* 2017). These four attributes of readiness for hospital discharge guided this integrative literature review.

Examining the findings of this literature review, between 20% and 45% of patients are not ready for discharge (Weiss *et al.* 2007, Satink *et al.* 2015) The percentage of patients insufficiently ready for discharge increases with age (Bobay *et al.* 2010) and using the operational definition above (Galvin *et al.* 2017) as a guide there are insufficiencies in discharge preparation in all four attributes (Boughton and Halliday 2009, Bobay *et al.* 2010, Rydeman and Törnkvist 2010, Fitzgerald *et al.* 2011, Hesselink *et al.* 2012, Gustafsson and Bootle 2013, Satink *et al.* 2015).

Support becomes increasingly important during the hospital discharge process as the patient ages (Bobay *et al.* 2010, Brent and Coffey 2013, Coffey and McCarthy 2013) as between 25% and 30% of older adults with poor discharge support are readmitted within 30 days (Bobay *et al.* 2010, Coffey and McCarthy 2013). Older patients rely on informal caregivers for this support (Boughton and Halliday 2009, Bobay *et al.* 2010, Rydeman and Törnkvist 2010, Hesselink *et al.* 2012, Satink *et al.* 2015).

Caregivers are identified by the patient as the person who would offer support post discharge (Coleman *et al.* 2006, Boughton and Halliday 2009, Gustafsson and Bootle 2013, Neiterman *et al.* 2015). However, discharge home is a time of crisis for caregivers (Boughton and Halliday 2009, Young *et al.* 2014, Ågård *et al.* 2015, Neiterman *et al.* 2015) because caregivers have insufficient preparation for the experiences that lay ahead (Boughton and Halliday 2009, Neiterman *et al.* 2015).

Caregiver needs do not align with those of the patient (Boughton and Halliday 2009, Fitzgerald *et al.* 2011, Perry and Middleton 2011, Coleman and Roman 2015) Studies

show that caregivers require their own support (Shyu *et al.* 2008, Shyu *et al.* 2010). These issues point to gaps in discharge planning and preparation of caregivers (Fitzgerald *et al.* 2011, Neiterman *et al.* 2015).

To conclude, this review highlights what research has been completed on caregivers taking the older adult home from hospital. No instrument exists to measure caregiver readiness for the hospital discharge of an older adult. Eleven studies were reviewed on caregivers concerns and experiences where approximately half focused on hospital discharge of an older adult however none of the participants were asked if they were ready. No study used the attributes of readiness to guide the questions and none has collected data within twenty-four hours of hospital discharge when experiences are foremost in their minds.

In view of the necessity of caregivers as a major support to their older adult relative during the hospital discharge transition (Bobay *et al.* 2010; Brent & Coffey 2013; Coffey & McCarthy 2013), caregivers of this cohort will be researched. This study proposes to use the attributes of readiness for hospital discharge (Galvin *et al.* 2017) to further explore the readiness of caregivers for hospital discharge of an older adult patient within 24 hours of discharge. The following chapter describes the research methodology for this study.

## **Chapter 3 – Methodology**

### **Introduction**

This chapter outlines the methods used to explore caregiver readiness for the hospital discharge of an older adult. This is a qualitative descriptive study and this chapter outlines and defends the methodology throughout, beginning with the aim of the study, followed with reasons for the research design used. The sample and setting are described with methods of access, data collection and data analysis. Detail on ethical considerations and methodological rigour are also provided.

### **3.1 Research aim**

The aim of this research was to explore caregiver readiness for the hospital discharge of an older adult within twenty-four hours. A dearth of studies on caregivers at the time of taking their relative directly home from the acute care setting was noted. Therefore, this study sought to collect data from caregivers as near to the time of discharge of their relative from hospital to home, as was feasible from an ethical and practical perspective. The older adults in this study are receiving a short period of care in a convalescence setting prior to going home. The attributes of readiness for hospital discharge developed in chapter one were used to guide the research and these are: physical stability, adequate support, psychological ability and adequate information and knowledge (Galvin *et al.* 2017). Therefore, the aim was to explore caregivers' perception of readiness in these four areas: their physical stability, their psychological ability to cope, support received and whether caregivers perceived they had adequate information and knowledge enabling them to be ready for the hospital discharge of an older adult.

These questions were developed by the researcher to clarify the concept of readiness for hospital discharge from the perspective of the caregiver of the older adult as this will contribute to nursing knowledge and evidence based practice in this area of healthcare (Leeman and Sandelowski 2012, Parahoo 2014).

### **3.2 Definitions**

For the purpose of this study the following definitions will be used:

Caregiver: A caregiver is defined as a person who has accepted responsibility for looking after a vulnerable neighbour or relative also called carer (Collins 2014). Studies have described a caregiver as the person who would support the patient after discharge (Coleman *et al.* 2006, Boughton and Halliday 2009, Gustafsson and Bootle 2013, Neiterman *et al.* 2015). In this study an informal caregiver such as spouse, adult child or significant other accompanied the patient from the local acute hospitals on the day of discharge. Therefore, the participant or caregiver in this instance was the person identified by the patient as the person who would give support at home.

Older adult: The older adult in this study is  $\geq 65$  years old.

Convalescence: Convalescence is the period during which recovery occurs (Collins 2014). In this study convalescence is a period of time post discharge spent in a convalescent service, in this case a dedicated bed or room in a long term residential facility where the patient is looked after by nurses who liaise on behalf of the patient with the multidisciplinary team such as physiotherapist, occupational therapist, speech and language therapist and dietician. The patient continues their recovery post hospitalisation usually for a week. The availability of convalescence care in these community units enable transfer of older adult patients from the nearby acute hospitals

much earlier in the recovery period, some of the patients are acutely ill and are not medically fit to go home without nursing care and supervision. Caregivers may need to prepare or modify the home if patient dependency increased. Time can be used to organise community services and help in the home. It gives caregivers of older adults' time to think, regroup, organise and rest.

### **3.3 Study design**

This study used a qualitative descriptive design, to explore caregiver readiness for the hospital discharge of an older adult. The literature review in chapter two identified concerns in the area of readiness for hospital discharge. The key concern is that older patients rely on their caregivers and cannot manage the discharge transition without them (Neiterman *et al.* 2015, Satink *et al.* 2015), however, caregivers are not routinely prepared to take their older adult relative home at the time of hospital discharge (Perry and Middleton 2011, Young *et al.* 2014, Ågård *et al.* 2015, Coleman and Roman 2015, Neiterman *et al.* 2015).

This review of the literature reviewed eleven studies around caregivers concerns and experiences of hospital discharge but concluded that there is no study exploring caregiver readiness for the hospital discharge of an older adult within twenty-four hours of discharge. In addition, there is no study that utilises the attributes of readiness for hospital discharge to guide the exploration and interviews with caregivers. Furthermore, no instrument exists to measure caregiver readiness for the hospital discharge of the older adult patient.

The decision to use a qualitative design was based on deciding which method would accomplish the study's purpose. Since the purpose of this study was to explore caregiver readiness for the hospital discharge of an older adult, a qualitative design

was deemed appropriate (Norwood 2010, Miles *et al.* 2014, Parahoo 2014). Qualitative enquiry is essential to assist the transfer of evidence to clinical nursing practice (Leeman and Sandelowski 2012, Colorafi and Evans 2016). A qualitative design aims to discover reality as it is experienced by the person, in this case the caregiver, to understand the meaning of the experience, hospital discharge of the older adult, from their perspective (Norwood 2010, Leeman and Sandelowski 2012, Vaismoradi *et al.* 2013, Parahoo 2014, Colorafi and Evans 2016). Therefore a qualitative design was chosen as opposed to a quantitative design as knowledge or findings in a quantitative study are usually presented in numerical or statistical language (Parahoo 2014).

Descriptive studies provide descriptions about phenomena of which little are currently known (Parahoo 2014, Colorafi and Evans 2016). A descriptive approach is well suited to uncovering mediators or causative reasons behind an outcome (Leeman and Sandelowski 2012, Colorafi and Evans 2016). Qualitative descriptive studies are grounded in naturalistic enquiry and therefore remain close to the truth or true experience because the researcher does not manipulate or interfere with ordinary events (Colorafi and Evans 2016). Other methods of qualitative design such as ethnography, grounded theory, discourse analysis or hermeneutic phenomenology employ a high level of interpretation therefore a qualitative descriptive approach was chosen in this instance (Sandelowski 2010, Vaismoradi *et al.* 2013, Parahoo 2014, Colorafi and Evans 2016). With a qualitative descriptive design, the researcher remains close to the data, presents the facts in everyday language and describes the phenomena under study (Sandelowski 2000, Vaismoradi *et al.* 2013, Parahoo 2014), this ensures solid findings (Sandelowski 2010, Vaismoradi *et al.* 2013).

### 3.4 Study sample

Caregivers provide informal support for the older adult patient at the time of hospital discharge (Bobay *et al.* 2010; Brent & Coffey 2013; Coffey & McCarthy 2013), and based on the literature reviewed in chapter two, caregivers of this cohort were the target population.

Qualitative samples tend to be non-probable or purposive because randomisation is not important and because the chosen participants suit the purpose of the study (Sandelowski 2000, Miles *et al.* 2014, Ilker *et al.* 2016). Purposive sampling is useful for obtaining broad insights and rich information on a subject where little is known (Kim *et al.* 2017) and involves identification and selection of relevant individuals who have the ability to communicate relevant experiences (Ilker *et al.* 2016). Convenience sampling is a type of sampling where subjects are chosen because they meet the criteria of the study, have proximity to the researcher and are willing to take part in the study, this is more common in quantitative studies (Ilker *et al.* 2016). It is argued that convenience sampling is not representative of the general population but convenience sampling can represent the population under research.

Purposive sampling methods emphasise obtaining a comprehensive understanding of the chosen subject until no new substantial information is offered by the subject or participant (Ilker *et al.* 2016). Therefore, a decision was made to recruit a purposive sample of caregivers from a community nursing unit, because in this convalescent setting the participants fulfil the inclusion and exclusion criteria, have relevant experience of the phenomena under investigation and gaining access to the site and sample was feasible (Miles *et al.* 2014, Parahoo 2014).



Studies using individual interviews use smaller samples (Kim *et al.* 2017) and according to Sandelowski (1995) an adequate sample size in qualitative research is one that permits a deep case-oriented analysis and results in a new and richly textured understanding of experience. Parahoo (2014) states that the purpose for which the sample is required should determine sample size as does Pope *et al.* (2000), but inadequate sample sizes can undermine the credibility of research findings and researchers have to make their own judgement (Sandelowski 1995). A smaller sample means more time is available to give to each respondent and the chance to become more in-depth in detail and analysis. Following review of the literature, a sample of ten participants, was deemed appropriate. Therefore, a carefully selected sample of ten participants was decided upon to provide representative data of the population from which the sample is chosen (Pope *et al.* 2000, Norwood 2010, Miles *et al.* 2014).

Questions around what data to collect and from whom was one of the most important decisions (Norwood 2010) and therefore inclusion and exclusion criteria were developed to ensure the sample chosen was representative. Inclusion criteria identify characteristics of those who will be sought as study participants and exclusion criteria identify characteristics that disqualify individuals (Norwood 2010).

### **3.4.1 Inclusion criteria**

Informal caregivers (non-paid) who are:

- Caring or supporting an older patient  $\geq 65$  years old recently discharged from an acute hospital to a short term of convalescence care with their final destination being home.
- $\geq 18$  years old

- Patient  $\geq 65$  years old

### **3.4.2 Exclusion criteria**

- Caregiver being employed by the patient
- Discharge of patient from a setting other than an acute hospital

### **3.5 Setting**

Adequate details of the setting should be included so readers can assess whether findings are comparable (Parahoo 2014). The setting for this study is a community nursing unit. Community nursing units provide a wide range of services including convalescent care and are primarily focused on the needs of the older adult (HSE 2019). In the current study the convalescent facility was part of the discharge process. This facilitated access to a sample of caregivers who had experienced the discharge process from the acute care setting with a view to taking their relative home. Thus, this sample met the inclusion criteria of the study.

### **3.6 Access to data**

Ethical approval was applied for and granted by Research Ethics Committee of the Cork Teaching Hospitals (CREC) (Appendix 16). Access to the sample was achieved by writing to the relevant director of nursing of the community nursing unit (Appendix 17). Caregivers were recruited by the researcher with the assistance of the nursing units' admissions nurse. The admissions nurse in the nursing unit contacted the researcher when a convalescent patient was expected. The researcher approached both patient and caregiver while in the admissions waiting area. The caregiver is the person of interest but speaking to the patient and explaining what the study entailed ensured

that both the caregiver and patient were comfortable with participation and also comfortable in consenting to partake (Ingham-Broomfield 2017).

The researcher made introductions, explained the study briefly and asked if the caregiver would be willing to partake in a private interview. A participant information leaflet with study details were presented to the caregiver who was given time to read and understand the study (Appendix 18). The researcher then re-approached the caregiver a little later and ascertained whether they remained willing to take part and if they were, a suitable time was arranged. Interviews took place in a private room with as little interruption as possible within 24 hours of the older adults discharge from the acute hospital.

Participants were recruited over a four month period in 2017 which was longer than originally anticipated. There were issues with convalescent referrals from the acute hospitals so there were less convalescent patients admitted during the time of data collection than usual. There were also unanticipated problems such as no caregiver available on the day of patient discharge and some of the patients had no caregivers or were unwilling to indicate who was supporting them at home.

### **3.7 Data collection**

There is a vast array of data collection strategies available but semi structured interviews are a common data collection tool used in qualitative studies and this was the chosen data collection method in this study (Sandelowski 2000, Parahoo 2014, Kim *et al.* 2017). A qualitative descriptive method does not have to use a theoretical frame work but if it does it is usually to support the development of the interview guide (Kim *et al.* 2017). This study used the attributes of readiness for hospital discharge

(Galvin *et al.* 2017) to guide the development of the semi-structured interview questions.

The semi-structured interviews used an interview schedule or guide (Appendix 19) which has a list of topics to be covered in the interview and this assisted the researcher to remain focused on the areas of interest (Miles *et al.* 2014). Open ended questions were also used as this is recommended for an exploratory study (Miles *et al.* 2014). All the participants were asked similar questions as this allowed for comparisons to be made across the respondents (Wertz 2011). Questions were asked in any order as the aim was to keep a natural flow and follow up with more detailed questions at the end if necessary (Norwood 2010). The schedule or guide used had four main questions asking caregivers if they perceived themselves to be: (i) physically ready, (ii) psychologically ready, (iii) if they had adequate information and knowledge and (iv) if they had support at the time their older adult relative was discharged from hospital. The interview began with an ice-breaker i.e. a broad question about caregiving and each interview concluded with a question around going home. Participants were then offered time to ask the researcher questions or to clarify any issues.

The decision to interview the caregivers privately came about from other researchers who studied similar areas declaring that the caregivers would speak honestly and would not be afraid of upsetting their relative if interviewed on their own (Boughton and Halliday 2009). Face to face interviews are more time consuming than other data collection methods but this is outweighed by the richness of the data (Parahoo 2014) and the interviews also allowed for clarification of issues or items that arise during the interview process. The interviewer also had the opportunity to record non-verbal behaviour that add contextual value later such as the mood of the respondent (Norwood 2010).

While using semi-structured interviews the researcher became the data collection instrument (Miles *et al.* 2014). Researcher intuition was used to probe and steer the interview (Parahoo 2014). A degree of trust is required and the researcher used her contact with the participant to build this trust. The emphasis was on facilitating respondents to talk freely (Wertz 2011). This method allowed the researcher into the personal intimate and private world of the participants. Therefore, interviewing these caregivers during a difficult time for them caused significant stress and distress to the researcher as identified by Toye *et al.* (2016) in their study on a similar topic. Researcher distress will be addressed later in this chapter under reflexivity.

Qualitative research enables the researcher to put responses in context which in turn places data in context. Because each interview builds on the previous, new leads that emerge can be probed further (Parahoo 2014). Interviews were voice recorded with participant permission to allow for minimal notes to be taken and transcribed verbatim afterwards (Norwood 2010).

Norwood (2010) recommends a pilot interview to assess the interview guide and the interviewer skills. The pilot interview assisted with testing of equipment and ensuring the interview recording could be heard properly afterwards. This interview also made the researcher aware of speaking less to enable the caregiver to talk more. It also showed that it is easy to rely on closed questioning with yes or no answers therefore, the interviewer was aware of these issues going forward. The researcher also noted that she had to keep reminding the caregivers that this interview was about them and not the patient.

### 3.8 Data analysis

As the aim of this study was to explore caregiver readiness at the time of the older adult relative's discharge from hospital and describe the findings, content analysis was chosen as the preferred method of data analysis. This method allowed participant responses to remain as they were (Sandelowski 2000). All qualitative analysis approaches begin with reading the data, all approaches are reflexive and all allow patterns to emerge (Pope *et al.* 2000, Elo and Kyngäs 2008, Wertz 2011, Miles *et al.* 2014, Parahoo 2014).

Qualitative descriptive data analysis using either content or thematic analysis allows the researcher to stay close to the data and low inference interpretation allows readers who are familiar with the topic to recognise experiences (Sandelowski 2010, Kim *et al.* 2017). Both thematic and content analysis are based on a 'factist' perspective, this perspective assumes the data to be a truthful description of reality as it is experienced (Sandelowski 2010, Vaismoradi *et al.* 2013). Both analyses examine narrative text by breaking the text into small units and submitting them to descriptive treatment (Vaismoradi *et al.* 2013). The difference between them is that content analysis aims to describe the phenomenon from the perspective of the participants (Elo and Kyngäs 2008). Conversely, thematic analysis applies minimal description to data sets and interpretation can be quite abstract (Vaismoradi *et al.* 2013).

Content analysis has been described as the analysis of choice in qualitative descriptive studies (Sandelowski 2000, Sandelowski 2010, Colorafi and Evans 2016). This study is concerned with meanings, context and consequences rather than the quantitative method of content analysis using statistics (Hsieh and Shannon 2005, Elo and Kyngäs 2008). The end result is a description of the patterns that emerged with a deeper insight

into the content (Sandelowski 2000, Graneheim and Lundman 2004, Elo and Kyngäs 2008, Sandelowski 2010).

Content analysis has been described as flexible though not simple (Elo and Kyngäs 2008, Sandelowski 2010). It may begin with a framework for collecting or analysing data but it is not necessary to stay within this framework (Hsieh and Shannon 2005, Sandelowski 2010). Because this study is researching an area about which little is known, Colorafi and Evans (2016) recommend using conventional content analysis where data were collected using a semi structured interview guide with open ended questions. The responses were then read and coded, notes were made and the codes were categorised. This approach to analysis is appropriate because it moves from the specific to the general (Hsieh and Shannon 2005). Elo and Kyngäs (2008) declare three phases to qualitative content analyses i.e. preparation, organising and reporting. A table showing the steps of these three phases is available in Appendix 20 and these steps are explained fully below.

### **3.8.1 Preparation phase**

The preparation phase began with transcribing the field notes or recordings into words to facilitate analysis. The researcher transcribed the recordings and this allowed for reflection. To ensure methodological rigour a description of the procedure is necessary (Reid and Gough 2000), therefore each transcribed interview was given a number and a colour to protect confidentiality and to enable the researcher to keep track of which caregiver said what.

The research question guided the third step which is the selection of meaning units (Giorgi 1985, Elo and Kyngäs 2008). A meaning unit is defined as words, sentences or paragraphs containing content related to the research question (Graneheim and

Lundman 2004). Elo and Kyngäs (2008) recommend taking as much time as necessary selecting the units. The beginning was chaotic with every word and sentence seeming to be important. The transcripts were not clear with participants moving back and forth from topic to topic. It was often necessary to go back and check the transcripts to ensure that a meaning unit belonged to a category. Quantity was daunting with nine interviews, that is close to one hundred pages of transcribed text, but keeping the research questions in mind assisted the researcher in seeking out relevant meaning units (Elo and Kyngäs 2008).

Meaning units were collected and organised using four Excel spreadsheets. The four sheets represented the four attributes of readiness for hospital discharge which were: Caregivers' physical readiness, Caregivers' psychological readiness, Support for caregivers and Information and knowledge (Galvin *et al.* 2017). Graneheim and Lundman (2004) call this process condensation as it refers to shortening the vast amount of text while preserving the core. The meaning units were entered in an organised fashion in rows across from the number of the original interview. Anything that was thought to be relevant to the research question was entered at this stage. Many sub categories were opened to assist with organising the meaning units and similarities were already emerging. This was carried out with every transcribed interview.

As subcategories were emerging the researcher worked in word using tables to show how the meaning unit became a condensed meaning unit and the sub-category to which it belonged. These tables were then organised into the four categories that emerged from the attributes of readiness for hospital discharge (Galvin *et al.* 2017). A table showing an excerpt of this stage is available in appendix 21.



### **3.8.2 Organisation phase**

To organise the data, the researcher reflected on the meaning of each meaning unit and its sub-category and the sub-categories were then placed into one of the four categories that were named after the attributes of readiness for discharge. In content analysis this phase is called the 'organising phase' where potential sub-categories collect the units of meaning (Elo and Kyngäs 2008, Vaismoradi *et al.* 2013). A sub-category is a group of meaning units that share the same values, messages or purpose (Graneheim and Lundman 2004, Colorafi and Evans 2016). To assist with assigning meaning units to sub-categories, the sub-categories were given names that defined their characteristics or attributes (Elo and Kyngäs 2008, Miles *et al.* 2014). Creating sub-categories by inductive content analysis, the researcher came to a decision, through interpretation, as to which sub-category each unit belonged (Giorgi 1985).

The purpose of creating sub-categories was to provide a means of describing the phenomenon under study, to increase understanding and to generate knowledge (Elo and Kyngäs 2008, Miles *et al.* 2014, Parahoo 2014). The next step was to combine similar sub-categories together to condense the text even more in order to describe the findings (Elo and Kyngäs 2008). As the researcher grouped similar sub-categories together some enlarged and some became irrelevant. This process was continued as far as was reasonable and possible (Elo and Kyngäs 2008). This analysis process was not linear as it went back and forth between the text, the units and the sub-categories (Graneheim and Lundman 2004).

### **3.8.3 Reporting phase**

The final stage of analysis is reporting the results of the previous stages (Vaismoradi *et al.* 2013). If qualitative data are compressed too much then the integrity of the analysis stage becomes lost (Elo and Kyngäs 2008). If the conclusions are summaries

without excerpts then the true richness disappears. Therefore, parts of the interview text shedding light on a specific areas were used to augment the description of the sub-categories (Graneheim and Lundman 2004). The main aim of data analysis was to provide genuine examples of the phenomenon under investigation (Elo and Kyngäs 2008). Remaining issues and limitations are articulated later in the chapter. To complete the study the researcher ensured the most effective truthful level of generality and this stemmed from the purpose of the study. The study findings are reported in Chapter 4.

### **3.9 Ethical considerations**

Ethics refer to the moral principles that guide decision making which arise from beliefs about what is right and wrong (Ingham-Broomfield 2017). The involvement of human participants in research is governed by several international codes such as Nuremberg (1949). In addition, Irish researchers must also fulfil any legal requirements such as confidentiality, anonymity and data storage as declared by the data protection acts of 2018. Irish nurse researchers must use the Nursing and Midwifery Board of Ireland (NMBI) guidance to ensure that ethical research principles and the protection of the rights of all those involved are maintained (NMBI 2017).

Ethical approval for this study was applied for and granted by [Research Ethics Committee of the Cork Teaching Hospitals \(CREC\)](#) (Appendix 16). The application outlined the measures to be adhered to from an ethical perspective throughout the research study from approaching the caregiver to publication of the findings. The measures or principals to ensure compliance were autonomy, justice, beneficence, nonmaleficence, fidelity and veracity (Dooley and McCarthy 2012, Ingham-Broomfield 2017).

### **3.9.1 Autonomy**

Autonomy refers to the right of a person to make their own decisions therefore every person involved in this study was fully informed and also informed of the right to refuse to take part and the right to withdraw from the study at any time without penalty (Dooley and McCarthy 2012, Ingham-Broomfield 2017). An information leaflet was given to each participant to ensure full understanding of the study (Appendix 18). This was followed by obtaining consent using a consent form containing clear information about the proposed study (Appendix 22). At the time consent was obtained, the researcher rather than the gatekeeper, ensured the caregiver was could understand the procedure and to freely give consent by reading the consent form aloud with the caregiver. The caregiver then asked if they understood the information given and if they were comfortable to partake in the research (Øye *et al.* 2016, Ingham-Broomfield 2017).

Qualitative research by semi-structured interview made it impossible to declare all the questions that would be asked, as researchers are unable to say how an interview will unfold. Therefore informed consent in this case was a process rather than a one-off event because the interview evolved depending on the caregiver and their experience (Parahoo 2014).

### **3.9.2 Justice**

In ethics the principle of justice means to treat all persons fairly (Collins 2014). Each participating caregiver had the right to privacy and fair treatment and confidentiality was maintained throughout (Dooley and McCarthy 2012, Ingham-Broomfield 2017). Transcripts were numbered and names, places etc. removed to prevent recognition. Data were stored securely in a locked file and a password protected computer, only

the researcher had access to the original transcriptions and the researcher transcribed the voice recordings, this assured the promise of confidentiality.

### **3.9.3 Beneficence or Nonmaleficence**

Beneficence means to do good or do no harm. This means that the researcher had an obligation to carry out the study for the reason of doing good by the participants (Ingham-Broomfield 2017). The researcher ensured that the participants had freedom from harm and exploitation (Dooley and McCarthy 2012) by providing clear information about the potential risks of taking part such as, anxiety and distress, and that sharing confidences could be upsetting (Ingham-Broomfield 2017). The participant information leaflet (Appendix 18) advised that participation was “voluntary” and the participant could “terminate the interview at any time”. In addition, participants were advised in the consent form (Appendix 22) that should they find the questions uncomfortable or upsetting they are “free to withdraw from the study at any time”. Furthermore, the semi-structured interview schedule allocated time at the end of each interview for participants to add any other comments such as thoughts, information or questions. The researcher also aimed to balance benefit versus harm during probing (Parahoo 2014).

The caregivers who participated in the study wanted to tell their story and there were good and bad experiences of hospital discharge. One caregiver was angry about her family’s hospital experience and wanted the chance to explain her issues to someone. During this participant’s interview, the researcher (who is a Health Care Professional) provided ample time for the participant to voice these issues, and listened attentively throughout. The researcher reminded the caregiver that she was not obliged to continue the interview. However, the caregiver wanted to continue to describe her experience,

this occurred during her interview with the researcher. She stated was glad to share her experience if it would help improve hospital discharge in the future.

At the end of the interview this caregiver was advised that she could speak to the team who looked after her mother during hospital admission. However, this caregiver stated that “she just wanted the whole episode to be over so that she could continue with normal life”. She was given the researcher’s contact details if she did require assistance or became distressed at a later date.

Another caregiver was upset and cried because it was the first time in a month any health professional had asked her if she was alright; she was recovering from breast cancer. Support for this caregiver was offered at the end of the interview by the researcher offering time to discuss her personal concerns and worries. Caregivers were referred to staff on the unit in which the older adult was convalescing if they had particular queries about their patient.

#### **3.9.4 Fidelity or Veracity**

In the area of ethics, fidelity means adherence to truth and accuracy in reporting the findings and veracity means honesty (Collins 2014). The researcher ensured that she was faithful to agreements and promises made to the caregiver such as maintaining confidentiality and that the caregiver maintained autonomy while being fully informed (Ingham-Broomfield 2017). The researcher also ensured that she accurately followed the design approved by CREC and honesty was maintained when reporting the findings (Ingham-Broomfield 2017). Almost all those interviewed requested an email informing them of publication of the study as they were interested in what others in their situation had to say.

### **3.10 Methodological rigour**

Rigour or (rigor) in qualitative research is not easy to define but the researcher needs to explain the steps they undertook to ensure a quality study (Reid and Gough 2000). Beck (1993) identified credibility, auditability and fittingness as the main standards of rigour for qualitative research studies whereas Colorafi and Evans (2016) use the terms trustworthiness and authenticity because they are similar to validity and reliability in quantitative research. Credibility, dependability and transferability are terms that have been used to describe various aspects of trustworthiness (Graneheim and Lundman 2004). Graneheim and Lundman (2004) suggest application of the concepts linked to the qualitative tradition and ensuring that all aspects of trustworthiness are intertwined. The five standards objectivity, dependability, credibility, transferability and application are used to assess the quality of qualitative studies (Colorafi and Evans 2016) therefore, these were the standards aimed for throughout this study.

#### **3.10.1 Objectivity**

Objectivity is defined as [a phenomenon] existing independently of an individual's perception and [a phenomenon] undistorted by personal emotion or bias (Collins 2014). In research, freedom from bias can be achieved by describing the study method, data collection and data analysis in detail (all of which are available above), and also by reporting potential bias and keeping original transcripts for possible evaluation (Colorafi and Evans 2016). The researcher bracketed or put aside her own perceptions, prejudices and beliefs so they did not influence the data during collection or analysis (Husserl 1962, Wertz 2011, Miles *et al.* 2014). Husserl (1962) describes bracketing as suspending previous knowledge of the experience. In the current study, the researcher put aside her own knowledge as a nurse and as a caregiver. The process of reflexivity facilitated the researcher in achieving this. In addition, the researcher allowed the text

‘to say what it is saying’ and did not impute meaning that was not there (Graneheim and Lundman 2004).

### **3.10.2 Dependability**

Reid and Gough (2000) use the word honesty in describing dependability in research while Colorafi and Evans (2016) use reliability or auditability. Graneheim and Lundman (2004) argue that dependability is the degree that data changes over time and decisions made by the researcher during the analysis process will increase or decrease dependability. Therefore, dependability requires consistency and consistency refers to the ability of another researcher replicating the same study using the same method and procedures and achieving similar findings (Reid and Gough 2000).

This study has laid out the methods used in detail, the same interview guide was used for each interview and triangulation from the findings back to the original transcripts was maintained (Reid and Gough 2000, Colorafi and Evans 2016). Agreement was sought from co-researchers (Graneheim and Lundman 2004) and authentic citations are included (Reid and Gough 2000) to increase trustworthiness or dependability.

### **3.10.3 Credibility**

Credibility is the truthfulness of the findings derived from the interviews (Colorafi and Evans 2016) or authentic representations of experience (Reid and Gough 2000). Selecting caregivers who would answer the research question was the first step (Graneheim and Lundman 2004). To ensure data collection from the correct participant the patient was approached and asked who looked after them at home this in turn ensured the caregiver fulfilled the inclusion criteria. The transcriptions were transcribed accurately thus ensuring credibility of the data (Parahoo 2014). Analysing

the data using content analysis ensured the research question was answered (Graneheim and Lundman 2004).

Selecting the most suitable meaning units also infer credibility. Therefore, illustrating how the meaning units were achieved as well as categorised assisted in trustworthiness (Graneheim and Lundman 2004, Hsieh and Shannon 2005). This procedure is explained in detail in the data analysis section. Credibility of research findings also deals with how well the categories report the data, in other words ensuring that nothing important is excluded or nothing trivial included (Graneheim and Lundman 2004). An audit trail can also be used to increase trustworthiness and Hsieh and Shannon (2005) recommend a type of triangulation to maintain credibility by constant checking of the data, peer debriefing and participant verification. Graneheim and Lundman (2004) declare that the value of dialogue or peer debriefing between researchers is not intended to see if each researcher would label and sort the text in the same way but would agree with the way the data were sorted and labelled. Participant verification was used by sending a copy of the interview transcript to the first participant, asking if she agreed with the content, to which she responded positively. In addition, regular consultation with co-researchers was maintained throughout the analysis stage.

The most important part of credibility is to ensure the findings make sense (Colorafi and Evans 2016) and these findings contribute to nursing practice (Reid and Gough 2000). This was achieved by providing rich, comprehensive descriptions as well as linking the findings to other research (Colorafi and Evans 2016).

#### **3.10.4 Transferability**

Transferability is the extent to which findings can be transferred to other groups or settings (Reid and Gough 2000, Graneheim and Lundman 2004, Colorafi and Evans



2016). To facilitate transferability a clear description of the context of the study, description of participants and participant selection, and full description of data collection and analysis are provided above (Graneheim and Lundman 2004, Elo and Kyngäs 2008, Colorafi and Evans 2016). In addition, presentation of the findings with appropriate quotations in chapter also enhance transferability (Graneheim and Lundman 2004).

Description of interpretations were given to enable other researchers to follow the process (Elo and Kyngäs 2008). Issues that prevented generalisability and therefore transferability were highlighted and other ways of testing findings were suggested (Colorafi and Evans 2016). Most importantly the findings in this study generate an accurate accounting of events that most people observing the same event would agree with (Sandelowski 2000).

Clarity in the data analysis process increases transferability (Vaismoradi *et al.* 2013) but Graneheim and Lundman (2004) indicate that there is always some degree of interpretation when analysing text. Heterogeneity decreases the likelihood of a biased sample (Graneheim and Lundman 2004). In the current study, every effort was made to include varied caregivers, for example, caregivers were not discriminated by age, gender, education or relationship to the patient.

### **3.10.5 Application**

Applicability is the extent with which findings are applicable in other contexts or situations (Reid and Gough 2000). To address application, findings of qualitative descriptive studies should be made accessible to participants, nurses and the general public through items such as; publications, poster presentations or conferences. This in turn may stimulate further research or promote policy discussions (Colorafi and

Evans 2016). Thus far this study has one publication in a peer reviewed journal (Galvin *et al.* 2017) and on completion a copy of the thesis will be available to view in the university library.

### **3.11 Reflexivity**

The emphasis in the current study was on facilitating respondents to talk freely (Wertz 2011). This method allowed the researcher into the personal intimate and private world of the participants. Reflexivity is an introspective process, and refers to the continuous process of self-reflection that researchers engage in to generate awareness about their actions, feelings and perceptions (Darawsheh 2014). Reflexivity requires researchers to consider their position in relation to their research. They reflect on their cultural background; thoughts; actions; emotions; assumptions; and unconscious responses, and how these factors may influence the research process and findings (Darawsheh 2014). Reflexivity thus enabled the researcher to provide a rationale for her research decisions, and in turn generate relevant findings.

Varying views exist on how reflexivity can add credibility to qualitative research. However, through reflexivity, researchers reflect on their thoughts, actions, assumptions, and expectations (Darawsheh 2014). In the current study the decision to explore caregiver readiness for the hospital discharge of an older adult arose since the researcher was working with this cohort in clinical practice. During the undertaking of an undergraduate degree the option to undertake a research degree arose. The supervisor for this degree also had a keen interest in the subject.

A scoping search was undertaken by the researcher and it was difficult to narrow down the studies and to decide which were relevant. A concept analysis was advised which was subsequently published in a peer reviewed journal (Galvin *et al.* 2017). The

attributes of readiness for hospital discharge then acted as a guide for the current study. In particular they guided the literature review, interview schedule and data analysis.

Much reflexivity was conducted throughout the entire study but the interviews required debriefing, as the caregivers allowed the researcher into their thoughts and feeling during a very stressful time. This in turn caused distress for the researcher. This was identified by Toye *et al.* (2016) in their study on a similar topic. The researcher debriefed as soon as possible after the interview. This was undertaken privately where the researcher took a moment to reflect on the issues raised during the interview and then to mentally put the information aside. In addition, being mindful of the ethical premise of 'do no harm' ensured that caregivers' needs were addressed. Offering to answer any questions that the caregiver had and signposting the caregiver to unit staff for further information also addressed caregiver needs. Contact details were provided on the participant information leaflet if the caregivers needed to contact the researcher at a later date. Completing the study ensured that participants' participation during a stressful time, contributed information to improve caregiver experience of hospital discharge of an older adult in the future.

## **Summary**

In this chapter an appropriate study design to explore caregiver readiness for discharge of their older adult relative from the acute hospital was identified. The methodology used is outlined in detail. The study aim and objectives were clearly described. A qualitative descriptive design was chosen with clear reasoning illustrated for choosing this method. Semi-structured interviews were chosen for data collection and the process of interviewing the nine respondents explained. The means of obtaining ethical approval and obtaining access to the setting and sample were included. The

method of data analysis is described in detail. Finally, measures to maintain quality control and rigour are outlined. The findings are presented in the following chapter.

## **Chapter 4 – Findings**

### **Introduction**

This chapter presents the findings pertaining to the exploration of caregiver readiness for hospital discharge of an older adult within 24 hours. The chapter begins with a description of caregiver and patient demographics (Appendix 23) to assist with ensuring methodological rigour (Sandelowski 2000). Using content analysis (Sandelowski 2000; Elo & Kyngäs 2008) the findings that emerged from the data are presented under the four attributes of readiness for hospital discharge (Galvin *et al.* 2017): Caregivers' Physical Readiness, Caregivers' Psychological Readiness, Support for Caregivers and Information and knowledge provided to Caregivers concerning the hospital discharge of the older adult.

### **4.1 Characteristics of the sample**

Nine caregivers were interviewed. All were female ranging in age from 30-79 years with the majority aged between 40-59 years. Seven of the nine caregivers interviewed were daughters to the patient; one was a spouse and one a niece through marriage. All of the caregivers had additional help from other family members except for one. Apart from one caregiver who was retired, caregivers were engaged in paid employment. Two of the caregivers in this study had other non-paid caregiving responsibilities. Education levels ranged from secondary level education to Master's Degree.

The Female (n=7) and male (n=2) patients were aged between 74 and 95 years old with an average age of 82 years. There were two distinct groups admitted to acute care: planned admissions (n=4) and unplanned admissions (n=5). Length of hospital stay varied; planned admissions were 6 to 15 days in duration, compared to 16 to 48

days for emergency admissions. Reasons for admission to hospital for the planned admissions were total hip replacements (n=3) and cardiac valve replacement (n=1). The reasons for the emergency admissions were: CVA (n=1); dizziness, nausea & ongoing neck pain (n=1); falls (n=2); and UTI/RTI (n=1) (Table 1).

**Table 1. Caregiver demographics**

DEMOGRAPHICS		
	Caregivers	Patients
Age	40-79 years	72-95 years
Gender	Female n = 9 Male n = 0	Female n = 8 Male n = 1
Relationship	Daughter n = 7 Spouse n = 1 Niece (in-law) n=1	
Education Level	Second level – Master’s Degree	
Admission type	Emergency n=5	Planned n=4
Length of hospital stay	16-48 days	6-15 days
Reasons for admission	Falls, Stroke, Gastric & Intestinal issues	Total hip replacement & Cardiac valve replacement

## 4.2 Findings

### 4.3 Caregivers' physical readiness

Physical stability is an attribute of readiness for hospital discharge (Galvin *et al.* 2017). Therefore, the caregivers were asked whether any health care professional had asked about their own health needs, to determine if they were physically able and consequently physically ready to care for the older adult. Responses indicated that these caregivers were never asked whether they were physical ready to care for the older adult during the hospital admission whether the admission was planned or unplanned. Responses included:

“No, no” (P1), and “No there was nothing, no” (P6).

Despite not being asked if she was physically ready to care for her relative who had a planned admission, one caregiver was positive about her ability to look after her relative:

“I have no problem with it...she's been backwards and forwards to hospitals quite a bit” (P7).

But in contrast, those caregivers, whose relatives had emergency admissions, were not physically ready to care for their relatives after hospital discharge and were dismayed that they were not asked. One daughter laughed and said:

“Are you serious? Ya right. Get her out of here.... the worst experience of our lives I swear to God it was brutal” (P2).

Another woman who was not asked if she was physically ready to care for her father revealed her recent experience with breast cancer:

“You see physically I’m not able either cause I have breast cancer. I’m only, you know what I mean, coming out of that...” (P5).

In addition, a spouse who cares for her husband, who had a planned admission, was also unwell and surprised that she was not asked about her health or physical ability to care:

“I had the cancer .... That was almost 25 years ago now. But I have skin cancer...Nobody, nobody and I didn’t tell anybody and I thought I’d get a chance to explain like I did to you now about my own health” (P9).

Since these caregivers were not asked if they were physically ready to care for the older adult after hospital discharge the researcher asked each of these caregivers if they were ready to care for the older adult following hospital discharge. Responses were varied as some caregivers understood that the researcher was asking about the caregiver themselves and gave clear answers, but others were a little puzzled. Therefore, the researcher probed further and discovered several issues that caregivers needed to resolve in order to be physically ready to care for the older adult after hospital discharge. In particular a feeling of being overwhelmed came to the fore.

#### **4.3.1 Being overwhelmed**

While all the caregivers in this study were caregiving to some extent prior to this hospital admission, caregiving became more intense for both the planned and the emergency situations. There was a sense of caregivers feeling physically overwhelmed. One daughter whose mother had a planned admission for a hip replacement explained:



“I’d say we were all overwhelmed, cause she was a very fit woman and active and she just went down all of a sudden ya... her mobility is kinda gone to be honest (P8).

While another daughter revealed:

“We don’t know what we’re doing, we actually haven’t a clue what we’re doing. Dementia is a terrible disease” (P4).

A daughter who is recovering from illness explained:

“I’m still tired like, I went back to work in September and I had to do an awful lot, so I was full on since September and then Christmas.... and I went back after Christmas and I was wrecked. I knew I was in over my head, it’s after catching up with me and then I said I have to back off a small bit...so I had just started to back off and.....so I’m exhausted” (P5).

In contrast, one caregiver was quite relaxed and said:

“Sure I don’t mind it; I don’t mind it at the moment” (P3).

But on probing explained:

“Well I suppose ‘twas landed on me d’you know” (P3).

While caregivers explained that they were overwhelmed by the hospital discharge of the older adult, there were certain activities that they felt helped them to physically prepare for the reality of the hospital discharge such as cleaning and renovating.

#### **4.3.2 Getting the house ready**

Some caregivers explained that being physically ready to take the older adult home was about having the house ready for their relative as having the physical environment

ready helped the caregivers to feel physically ready. Some of the older relatives were going to stay in their caregiver's homes until they fully recovered but almost half were going home to their own homes which needed extensive cleaning and renovating. Those caregivers whose relative had an emergency admission divulged that there was a sense of chaos and unexpected issues cropped up such as dealing with their relative's attire and renovating or cleaning their relative's house. There was a sense of 'putting everything back together' and 'making the place nice'. One caregiver and her family were making a bedroom downstairs because their relative would find the stairs difficult, she described:

"The house is torn up at home cause we've had to break through the back kitchen wall to make a handicapped shower unit and toilet, we are going to have to switch the upstairs furniture down and the downstairs furniture up and you see the downstairs room is an exact image of the upstairs room so my husband had an idea, that how bout we put the bed in exactly the same position so on her left hand side will be the window and her dressing table will be the same" (P1)

The caregiver recovering from breast cancer, looking after her father, who had had a stroke and suffered decreased vision, also did extensive work to his house even though she herself was unwell, she described:

"I done a big clean up at home but, I haven't moved anything strategic like, I dumped old clothes and stuff I made it actually easier to get at stuff so when he goes home...and now I'm watching my phone cause the carpets are coming today and the new bed cause he needed a new bed . I mean I spent all day

Saturday cleaning up the house. I have lymphedema as well in my breast which is worse” (P5).

Another participant who needed to get a bus to access the shops revealed:

“Tomorrow now I have to spend time looking for a commode... we’ve no toilet downstairs and we’ve a very steep stairs to go up....I’ll be there on my own I’m going to the medical centre” (P9).

Amidst doing their best and creating a suitable living space by cleaning and renovating, difficulties emerged for caregivers.

#### **4.3.3 Difficulties experienced**

Throughout the discharge process caregivers experienced difficulties managing their relative due to the nature of their illnesses and its impact on their mobility as some of their relatives were uncooperative. One caregiver was appalled with what her mother was wearing when she was admitted to hospital:

“You see another thing we had to deal with was the clothing, if you saw what came off her when she came into the hospital. T’was like 50 years old. She had manky underwear...so we were trying to get her to wear a pants and she didn’t know about probably cause it wasn’t very lady like my sister finally convinced her... she’s like a fish out of water...and she’s going back to her skirts as soon as she goes home... but she can’t bend down... she is becoming more difficult”

. This caregiver went on to explain:

“And you see I’m after washing all her jumpers because they needed it, as she wears them and puts them back into the press and they were all once and twice and three times worn...And the whole bed you should have seen it! It was like

a nest made by birds, layers upon layers upon layers of furry things and socks and bed cardigans you name it. I said I'd throw them out and I'm going to get her a lovely 14.5 tog quilt my sister says "don't! Don't throw them out". I did throw the pillow out she's going to kill me when she finds out" (P1).

Another caregiver who cares for her Dad, who has impaired vision, was trying to help by offering suggestions but they were not received well:

"I'm afraid that he's going to go home and he'll be afraid to come out, so he's gonna need like, I kind of said to him like an assist dog, I did mention guide dog but that didn't go down too well, that was when he was in hospital" (P5).

One caregiver who works on a farm talked about the difficulty in finding the time to look after her mother:

"Our farm is very busy like and whatever so I'd only have the middle hours in the day kind of like and so" (P2).

Even though caregivers were overwhelmed and wanted to do their best for their relatives they also worried about how they were going to sustain this level of care long term.

#### **4.3.4 Sustaining**

When caregivers were probed about being physically ready to care for their relative on a long term basis they mentioned worries about sustaining the current level of care that they were providing. A caregiver whose mother is coming to stay with her after her period of convalescence worried about sustaining this physical level of caregiving, running a farm and looking after a family, said:

“Long term I just wouldn’t be able to... sustain it like no, because we start around half seven in the morning like and I am back then maybe half eleven twelve o clock and this time of year like and we start then again at six and I mightn’t be back then again until like til nine o clock in the evening and there’s other stuff to be done in the meantime..”(P2)

Another caregiver who also cares for a relative who lives with her brother, who also requires care but this care is provided by someone else, worried about sustaining the current level of caregiving:

.“D’you know now you’ve no idea now like the two of them like d’you know they’re like children the two of em...looking at it now it’s going to get tough going like, I don’t know about it, I’ll see....” (P3).

These caregivers were more realistic of their expectations explaining that this level of caregiving would be unsustainable. However, even though these caregivers experienced difficulties they still wanted to do whatever is best for their relative.

In summary, caregivers in this study had never been asked if they were physically ready to care for the older adult either during their recent hospital admission or the time of hospital discharge. During the interview on asking if they were physically ready to care for the older adult caregivers responded that did not mind looking after the older adult and some said they were happy to do so, but the increased work load and pressure added to their daily lives is evident. Most were overwhelmed and some caregivers were exhausted. Some caregivers had difficulty in physically managing the older adult due to the nature of the illness but nonetheless ‘wanted to do what’s best’. Sometimes the older adults were uncooperative and this added to caregiver stress. While caregivers are willing to do this amount of physical caregiving including

cleaning and renovating in the short term, they worry about sustaining the level of caregiving required into the future.

#### **4.4 Caregivers' psychological readiness**

Psychological ability is an attribute of readiness for hospital discharge (Galvin *et al.* 2017). On exploring caregivers' psychological readiness to take the older adult home from hospital they were asked how they felt about being an informal caregiver. However, they did not appear to understand the question. The researcher then rephrased the question to ask if caregivers were ready to cope with the hospital discharge as coping is an antecedent of psychological ability. Participants who attempted to answer this question kept referring back to the older adult. On further probing some of caregivers' own feelings were expressed with admissions of stress and worry as well as not wanting to think towards the future too much because they were worried about what may happen.

##### **4.4.1 Coping**

It was evident that knowing they were doing their best for the older adult assisted caregivers in coping and feeling ready to go home. One caregiver said:

“I suppose I'd be, being honest with you at a time like this in a family, you don't think...” (P1).

The caregiver who looks after her mother with dementia said they were coping until this fall:

“Aamm, she made us all promise I suppose a couple of years back that we'd never put her in a nursing home so, we're trying our best like but looking after

her ourselves just isn't enough so we're getting somebody else in as well so we've been doing a rota" (P4).

Based on this promise this family have thought about the future and their long-term plan is to get a lady to perhaps live with their mother. However, they are unsure how amenable their mother will be to this plan. Long term, another daughter is encouraging her father's independence because she believes this will assist everyone to cope with the situation. She has spoken to her Dad about it, she said:

"Now I still believe he can live at home like, I'm trying to you know...and I said it to him there like, cause when you have your own house you're going to have your own surroundings and you'll know where everything is..." (P5).

One caregiver stated:

"Do you know you just get on with it" (P6).

While another admitted that it's not easy:

"Well it's hard going now at times definitely" (P8).

Caregivers admitted to having worries and concerns about their relative while discussing how they were coping, particularly as they looked towards the future.

#### **4.4.2 Concerns and worries**

Almost all of the caregivers in this study indicated that they had concerns in the short and long term. One caregiver voiced:

"I was very concerned last night cause my sister rang me and she said she's in bits" (P1).

This caregiver's mother is 95 and was very independent prior to the hospital admission, she went on to explain:

“It made me feel very, very, very sad; to see my mother loose so much cause she was always praised for her complete independence, and the closer it gets to gaining back her independence the less resolve she's showing” (P1).

On inquiring about the future this participant said:

“In the long term I suppose...we're not looking at the long term. We're taking the next stage we're going to be very positive about here....this has a different view on rehab... and we'll get the hair and the opera...” (P1).

She then went on to explain that she had tried speaking to her mother about the future:

“Every time I approach it with her it's 'how will I manage at home?' I think from her own perspective she is allowing helplessness set in. And I think it's like a letting go that I would never have envisaged a year ago” (P1).

Another caregiver who was concerned about her mother's pain and her dietary intake explained:

“Ya, she'll eat one day and she won't eat the next. Cause she'll have the pain...But having said that like she's very bad cause she'll eat stuff I reckon she should be on a certain diet like” (P2).

This caregiver is bringing her mother to her home after the period of convalescence but would not like to have her living with her long term. Another caregiver was worried about her relative's mobility and dexterity:



“I dunno now getting out of the bed and things... but aamm... she hasn’t gone to the toilet on her own now or anything in the hospital... you know so...” (P3).

On asking about what she thinking about for the long term she said:

“I think myself down the line she’s only suitable for a nursing home like that’s not for me to say like that would be up to her niece” (P4).

The caregiver whose Dad has developed poor sight, mentioned being worried about how he will manage:

“He’s very blind and he’s only now, like they’ve left him out and to be fair they did their best to try and tell him but like he really genuinely believed that they were wrong, its only there now he’s going ‘oh my god I can’t see’ ... “(P5).

Then she recounted that she likes to go away with her family during the summer and this is now another added stress:

“God we’ll just have to wait and see and you see I go away every July” (P5).

One caregiver was worried her relative was not able to go home without the convalescence and may still not be ready after her convalescence week:

“We were worried that she wouldn’t be able and she certainly wouldn’t be able to go home at the moment. Well we are a little worried about her but sure we’ll just have to deal with it and we will see how we get on now Monday” (P6).

Another caregiver was worried they might be facing into a long illness like a previous hospital discharge where her relative got a post procedure infection:

“What I was worried about was that last year she had these lymph nodes removed from her leg and she was discharged after about a week I suppose and

she was only home three or four days and she got a bad infection... Ya the worry...the same thing like she wouldn't be able to do anything... she has come on since the weekend like she was very weak there at the weekend and they had to give her blood and all that" (P7).

Only one of the caregivers was spoken to by a health care professional regarding the short and long term, she said:

"They had spoken to us before she came out of hospital cause we didn't know what you know our short or long term plan was for Mam so they just went kind of through everything and maybe getting home help and stuff for her. I suppose we're ok now cause we know she's here and she'll get her physio and stuff done I suppose when she comes home we are going to be nervous, worrying long term for herself, will she continue her physio... we hope she will" (P8).

Regardless of the difficulties these caregivers were experiencing they were continuously advocating and watching out for the older adult.

#### **4.4.3 Advocating and watching out**

Advocating and 'watching out' for the older adult was a big part of being a caregiver prior and during hospital admission to the acute care setting. Caregivers want the older adult to have the best care possible as this promotes the caregivers' psychological wellbeing. This in turn assists caregivers in feeling ready for hospital discharge. One caregiver's experience in advocating for her relative was difficult. She knew on several occasions that her mother was unwell and had to keep asking for help until they resolved the problem, she said:

“Prior to hospitalisation...so I rang the doctor and I said she’s just out of sorts there’s something wrong with her like she’s just not right....the medical assessment unit said ‘you can go home we found nothing’ and so we went home... She spent two weeks in my house then with chronic diarrhoea and vomiting... I rang the doctor again and I said this can’t go on at all like and so he said right the only thing you can do is go back to the hospital and she was admitted practically straight away” (P2).

Then because her mother had eaten nothing during the admission and she was just not happy with how she was, she knew she was not ready to take her relative home in her current health condition, she spoke out again:

“The fact that she hadn’t eaten anything in hospital they didn’t ask had she eaten now she didn’t eat a bite nobody would look check or do anything ..... And by the time she was leaving hospital she was kind of vomiting so anyway...I kind of lost the plot and...The nurse in charge and...I said look she’s not eating how are we going to care for her at home and she’s getting sick what are we going to do with her and the pain was bad at that stage and ahh...We got two more days” (P2).

Then even though her mother was readmitted to hospital this caregiver still checked on her every day and again realised she was very unwell:

“Now I’d been in there Monday, Tuesday, Thursday, Friday and my sister was in on Saturday and Sunday..... and Saturday morning then cause I’d always ring her I’d ring her a lot in the day like and aamm I rang her and I knew straight away that she wasn’t right..... so I rang my sister and I told her to go

in as quick as she could and aamm when she went in she was in the high dependency ward cause she was after aspirating during the night” (P2).

Another caregiver who takes care of her relative’s finances revealed:

“I get her pension cause she was getting someone to get the pension and she be giving them €20 to go for it and she’d be short and she’d have no money then so...I think when you’ve no voice in these places for her d’you know now she’d have no one to talk up for her what can you do like? You can’t just let a person you know” (P3).

One daughter was very upset and could not understand that her mother with dementia was moved from room to room several times, she explained that eventually she had to put her foot down:

“Then she was moved round wards... and with the dementia patient I just don’t know ...I just don’t think...like how...I, I, I couldn’t get my head around why they would move somebody with dementia...and they moved her four times. And they were trying to move her a fifth time and I just like put my foot down....” (P4).

She disclosed further how she and her sisters felt accused of neglect and she was very upset because they give a significant amount of time looking after her mother, she explained:

“Like the admission was very stressful like they put us under a lot of stress, under, like I mean obviously they, they had, the circumstances and you know but I think like I think it’s quite evident that Mom is not neglected. Like I mean and I think that really got to us.... I know like she... we all... but then it’s more

the tone and we've all taken significant time off work because you couldn't leave her there on her own" (P4).

Another caregiver who felt that the staff were happy to let them look after her father to save them some extra work declared that:

"They were just so happy that we were there. They are so happy that we're there cause it's thank God we aren't going to be landed with him" (P5).

This family had a poor experience on a previous discharge where her Dad was not given a diagnosis or information about his recovery, the caregiver went on to explain:

"They left him out after 24 hours with a canula stuck in his arm, and told him he had a concussion. Three weeks later we found out he had a bleed in the brain. He actually went through the horrors God love us, he thought he was actually losing his mind. Cause no one explained to him that it was a brain bleed trauma...he was never actually discharged properly from the hospital" (P5).

While caregivers wanted to advocate for their relative and found this to be a necessary part of caregiving, they also experienced challenges.

#### **4.4.4 Challenges**

Caregivers experienced difficulties dealing with the older adult and some caregivers experienced difficulties with other family members. This added more pressure and more stress to their daily lives. One family spoke about difficulties in dealing with their relative from a safety perspective and how this agitated the entire family:

"If she'd have listened to my husband and myself and had a walking stick around the house and it was her slipper jagged... unknown't to us she'd been

painting... and while cleaning up the blood and the morphine stuff after the ambulance my husband had to go out and put away the paint cans, the papers, fold up the little step ladder and that's what she was doing and she was hiding it, she was touching up...around the house..." (P1).

Taking into consideration that this relative is 95 years old, this caregiver went on to divulge:

"I'll tell you she'd try your patience, oh Christ she would. I'm being very honest now, she would seriously" (P1).

She then disclosed some family issues:

"We are probably more than dealing with Mam at the moment but we are dealing with serious marriage problems that seriously came to a head with my sister and my brother in law, mental health issues and all that which were lying down here under the surface and that Tuesday night that Mam was taken away in the ambulance, it exploded" (P1).

And she realised that this extra stress and pressure revealed family problems that not everyone was aware of:

"I suppose I'd be, being honest with you at a time like this in a family, you don't think, at a time like this coming from a family of six, it shows the fissures and the cracks in a family" (P1).

Another caregiver explained that she would offer help to her mother but it would be refused and then her mother would still complain:

“She’d gone shopping and we were saying to her like and cause she’d be complaining the following day and my back is killing me and we’d be saying to her like sure if we did the shopping sure there’d be no problem like that you wouldn’t have the pain in your back and she’d like say “no, no, no, no, no I’d have to do it myself” (P2).

She then explained that she finds it very difficult when her mother comes to stay because she criticises her husband, she said:

“It’s an awful thing to say but she’d be kind of like anti-men like and she would aamm my husband now cause he works hard and whatever aamm...’you shouldn’t be working to that level’ and this kind of thing and I won’t cope with that at all” (P2).

Another caregiver bluntly describes her caregiving life:

“Allergic, allergic, my mother is dead twenty-two years and my brother and himself started to come to me then straight away for their dinners and whatever so, so then my brother got married, eventually, so don’t get me wrong that’s not fair cause he’s brilliant, and he’s always been very good, but I’m sensible enough to say not to move in with me. I couldn’t, he’s no trouble and he’s good but I couldn’t I’ve done twenty-two years...and I...mornings an all even though he lives at home, he spends a lot of time in my house” (P5).

She went on to explain what it was like when her daughter was doing her leaving cert exams, how her Father was deaf and had the volume of the TV up too high:

“I just.. like my daughter was doing her leaving cert two years ago like and the television... he tells everybody that he’s not deaf that he has perfect hearing

but the television was blaring and she's upstairs trying to study, 'would you mind turning down the television' and like the whole parish can hear the television smaller things you know. And as I said, he has a heart of gold really good to me but, but, I couldn't live, I couldn't handle living...." (P5).

More caregivers have issues where their relatives have been offered supports and the relatives refuse even though the caregivers need those supports to assist them in their role, for example:

"She was offered a place in a day centre before and she wouldn't take it" (P6).

And another caregiver explained about how her spouse refused some convalescence care without discussing this:

"I had hoped we were getting two weeks and I didn't know he was getting two weeks I thought twas one. But my friend told me that twas two weeks you'd get so he said it to me he admitted to saying he only wanted one week he wouldn't come at all if he got away with it" (P9).

This section emphasises that caregivers are not routinely asked about their feelings or if they are psychologically able to cope with the transition of their older relative from hospital to home. There is very little discussion during the hospital stay about getting ready for issues that arise due to hospital admission. All the caregivers were worried about various issues revolving around their relative and did not stop to think about themselves. Caregivers set their emotions aside, older relatives could be difficult and caregivers had to get on with it whether they were ready or not. While wanting to do what's best and get ready for the older adults homecoming, caregivers are not given a



lot of guidance from healthcare professionals. Supports for caregivers are reported in the next section.

## **4.5 Supports for caregivers**

Support is an attribute of readiness (Galvin *et al.* 2017) and caregivers in the current study indicated they required formal and informal support to enable them be ready to take the older adult home. All of the caregivers in this study had family support (informal), but offers of formal support varied from caregiver to caregiver.

### **4.5.1 Family support**

On asking caregivers about support they received during the hospital discharge most caregivers indicated they had informal or family support from other family members in varying degrees. Some had siblings to share the workload and some relied on their teenage children to help out. Varying amounts of help was given from other family members. One caregiver expressed that:

“Well at the moment tis fine cause between all of us we’re working around it d’you know what I mean we’re balancing out” (P8).

While another caregiver declared that:

“I have good friends” (P9).

Another relative lived with her brother but they both needed care and while this caregiver was the main caregiver she liaised with a more direct relative who lives a couple of hours away for help and advice but did not like to bother her too much as this person had other own caregiving responsibilities:

“Well any time I said anything to her niece like you know she would do it but having said that you know she has two young children and her mom then is in a nursing home as well....” (P3).

One caregiver was sharing the caregiving responsibilities with two sisters. However, one became acutely unwell at a time when there was more caregiving necessary and the responsibilities were now divided by two:

“She was one of the main help it was a younger sister, another one, it was just another thing...” (P1).

One daughter was not impressed by her brothers’ assistance:

“I wouldn’t leave like those ‘g\*\*\*\*\*s’ of brothers of mine..., they’ll come out and visit now no problem, sure that’s the easy part, and then they’d say well I visited Dad last night for three hours and then I’d say sure I spent four hours cleaning the house” (P5).

However, in contrast this caregiver is happy with the help she gets from her two teenage daughters:

“My daughter came down from college yesterday from Galway and she’s 20, she’s brilliant. They both are. My youngest is only sixteen, so I’ve said to Dad one of the girls will collect you on Wednesday and they have food in and all the rest of it” (P5).

While all the caregivers in the current study had informal or family support, formal supports were not as straightforward.

#### **4.5.2 Formal support**

Formal supports come in many guises such as nurses and other healthcare professionals during the hospital stay as well as community supports such as respite, the PHN and GP after discharge to name a few. On probing caregivers about formal supports offered and received during their hospital stay, offers varied. Some caregivers were offered formal support but some had to ask.

#### **Convalescence**

While indicating that this period of convalescence was in itself a form of support and inquiring about what they would have done without it, these caregivers could not have coped with going home directly from hospital. One daughter explained:

“No I couldn’t have coped personally and my sister would have found it very, very difficult” (P1).

Another caregiver knew she could not have taken her relative home directly from the hospital and when asked about what it would have been like if she had taken her relative directly home, she said:

“Well I’d hate to see...” (P2).

Another daughter who really wanted her mother out of the acute setting but was not ready to take her home, said:

“The hospital told my sister that they found a place and she said we need to get her out of there as soon as possible and get her in here...look we can take a breath now and see how she gets on here and hoping for the best...” (P4).

One caregiver was more aware that her relative was not ready to go home and her relative also knew this:

“She knew herself that she wasn’t up to coming home” (P3).

But the offer of convalescence was inconsistent and did not come to all. One caregiver had to ask:

“I said is there any way she can get respite or something like that for whatever. So I went in Thursday and I spoke to her again and she said ah the discharge co-ordinator is involved now. And then she said ‘we will try and find somewhere’. So Friday, Thursday night Mum was told she was coming to convalescence Friday” (P2).

Another caregiver voiced her relative was not ready to go home and said:

“Oh they were sending her til I said that she wasn’t, she wasn’t suitable for coming home!!” (P3).

As did this caregiver who was very upset that she had to push the healthcare provider to get the offer of convalescence:

“They never offered they never said you know there may be a place, like you said they never asked me was I ok...they never said aamm that there may be a place, a step down place, that would help for a week, you know they never offered any of that I had to ask, I had to keep pushing and pushing and pushing. He was supposed to be going home today but and then they came last night when they got word” (P5).

Those caregivers whose relatives had planned admissions for surgeries (n=4) had more of a say and choice in the matter. One caregiver was unsure that convalescence was the right ‘thing’ for her mother but when she heard that there would be physiotherapy and activities she was delighted:

“We were undecided whether we were going to put her into convalescence or not because we didn’t know how she was going to be after the operation. We’re delighted now with the week ya. Aamm but you see we probably would have managed you know we probably would have had no other choice but to manage...now we can make some arrangements.” (P6).

Another caregiver with a planned admission said about her relative:

“Well I think she needs it, it would be too soon for her to come home being honest...” (P7).

And she admitted that without it she may not have managed:

“I mean I suppose you’d have to make do but I, it would have been difficult because you know she was going to be quite weak and she’s you know a big woman and trying to manage her you know...” (P7).

An older spouse really needed this support because she said:

“I don’t think I’d be able to go straight home. No I was terrible happy and very grateful really and I never stop worrying...” (P9).

While another caregiver expressed “we were delighted” (P8) when she was offered a period of convalescence for her relative.

## **PHN Referral**

One of the main community supports post hospital admission is a visit from the PHN. On inquiring whether their relatives received a referral to their PHN, two caregivers were happy with the PHN service:

“We’ve a great health nurse...Whenever we want her we just pick up the phone dressings or anything like that she’s fantastic” (P6).

Another caregiver who has contact with her PHN said:

“She would call” (P8).

Two caregivers were definite that there was no referral and others knew their PHN from before but were unsure whether she would call again:

“Like I know the public health nurse was calling last year so whether she’ll call again...” (P7).

And some caregivers were going to contact the PHN themselves:

“My brother has now it’s funny cause he was saying that he’d get on to them...but like I dunno he would know her quite well like” (P2).

One caregiver who has not previously had the PHN visit her husband was going on the bus herself to the health centre to try and get a commode and find out more about the PHN. On asking her if she has had previous contact with the PHN she responded:

“I’m not but from tomorrow I hope I will be. Ya...” (P9).

One caregiver who had the PHN call previously to her mother was upset that an offer of respite was not given to her mother who has dementia. This caregiver is under a lot of pressure and stress and could do with that extra support as she explained:

“No...She never told us about respite and now we’ve missed the allocation for the year and we really could have done with it. We spend every week now worrying about her we’ve the app going off and checking it and checking it and it never ends...” (P4).

### **Additional Formal Supports**

On asking caregivers about the offer of additional formal supports, responses varied. One caregiver had support from the Community Occupational Therapist and one caregiver was told she could ring the hospital if she had any questions after going home. One caregiver’s relative has home help everyday but in contrast, another caregiver asked for home help and was refused:

“I asked for home help and they said he wouldn’t be entitled to home help. Because he can dress himself and why I want home help is that I would love somebody to be in with him just to call in the morning and make sure he’s ok because he’s very blind” (P5).

Another caregiver’s relative had been offered home help previously:

“Ya they previously spoke about getting a bit of home help for Mam” (P8).

One caregiver had someone out checking the house and on probing further about the nature of this visit, she said:

“But we had someone out to the house checking it and it was...ya the home care package, ya, ya...” (P6).

### **Financial Support**

With regards to financial support, while the researcher did not ask this question directly, two caregivers volunteered the information. The first was the participant caring for her 95 year old mother who was told she did not qualify for a medical card due to having some savings, she said:

“Well we’ve a fierce problem there in so far as, Mam, because she felt she should keep some money in the post office, not a lot. So she has a little in saving for the rainy day, and because she has this little savings she’s not going to qualify for a medical card we think, we’re researching it at the moment so as regards what the community can offer, it would be marvellous if she had the medical card and we could follow on but we don’t know really...” (P1).

The other caregiver who volunteered financial information had a completely different outlook because they could afford and were willing to pay for services. However, even though they had a good health insurance package this caregiver said:

“We’re lucky financially...no qualms about paying. My mum pays like we all subsidise Mom’s health insurance, so she can have the best care, like she... it is not cheap...like she has the top...she can get a private room in the best private hospital. And I’m not saying she should get special... but why are we paying this if we can’t even like...Like we’ve all taken significant time off work because you couldn’t leave her there on her own” (P4).

Her argument being that they had already paid for health insurance to prepare for the hospital scenario but still had to take time off work to look after their mother while she was in hospital therefore, losing personal income.



In summary, on inquiring about supports offered and received to caregivers to assist them in being ready for the older adult's discharge from hospital, it is evident that supports were inadequate. Therefore, not all of the caregivers in this study were ready for hospital discharge of an older adult. Convalescence was a big help and the participants were happy with this support service. However, entitlement to convalescence is an issue of uncertainty as participants did not understand whether they were entitled to convalescence or not.

None of the participants in this study knew if a referral had been sent to their PHN on discharge. However, some caregivers had contact already and were not worried about this, but those who did not know about the PHN support service did not understand how to negotiate the system and did not know if they were entitled to the service. In addition, those who were willing to pay for additional help did not have a better experience. Those who had emergency admissions had a poorer experience overall regarding the offer of all supports. Those who had planned admissions seemed to fare better as the offer of convalescence support was part of the plan of care, prior to the hospital stay.

#### **4.6 Information and knowledge**

Information is one of the attributes of readiness for hospital discharge (Galvin *et al.* 2019). Since information is a prerequisite of knowledge, information provided to caregivers will be reported. On asking caregivers about the information received from health care providers prior to discharge, some were happy with the information received and others were less so. One caregiver who had a good experience said:

“They were A1. They were utterly fantastic you could not believe you know with all the complaints about the healthcare we haven't one complaint, not one.

The humanity the patience the professionalism it was incredible from the outset...” (P1).

As did another:

“Now we’ve had a very good experience with um, now I wouldn’t have any problem with them now thank god ya...” (P8).

Other caregivers were unhappy with the information they received. On asking one caregiver if she was given adequate information she laughed saying:

“Nothing...a letter for the convalescent centre that’s it. No, (laughs) No, No, No, No, No. We were told that we’d have a discharge person, who would bring us in for a meeting and they would discuss all the options with us. And they would tell us where to go. But like did we meet that discharge person, no, not at all. No, no, I got handed a brown envelope aamm I packed up the bags and the only thing they gave me was a porter to bring her down to the car. And to be honest I was so sick of it I wanted to get out” (P4).

On exploring information provided to caregivers, different types of information necessary for the caregiver were highlighted.

#### **4.6.1 Types of information**

##### **Convalescence**

As already alluded to in the section regarding formal supports, information regarding convalescence was erratic. One caregiver was informed about convalescence by one of the medical team:

“The doctor rang me, one of the team, and she said she was going to the nursing home” (P3).

Two caregivers were informed by a discharge co-ordinator. But information came from someone other than the healthcare provider for another caregiver:

“Somebody told me that he was entitled to two weeks in a nursing home, because he doesn’t want to go home, he’s after getting an awful fright. (P5).

Another caregiver who was unhappy with the information given, revealed that they did not even get directions to the convalescence centre:

“Nothing. Nothing. Basically she was wheeled down to the discharge place and that’s it. Now I didn’t collect her now twas my sister. Because it was a bad time for me, so my sister was giving out yards cause she rang me cause she couldn’t find this place like, but she was wired in the car cause Granny was giving out... And I could hear my sister giving out like where is this place....“ (P2).

## **Diagnoses & Medications**

Information regarding diagnoses and medication was fragmented and erratic. One caregiver whose relative had a planned admission received information on what procedure was done:

“They gave us aamm, her, the procedure she had done and how she would deal with it over the next couple of weeks yes” (P6).

While information given to some was adequate for others it was incidental/ or ad hoc as evident by another caregiver:

“No I was told nothing anyway ya. The doctor rang me; one of the team and she said she was going to the nursing home and I said ‘how was she?’ and twas only then I knew she had pneumonia and they said she’s fine...” (P3).

One caregiver got information by chance from the Occupational Therapist (OT):

“It was only kind of a by the way that she said that he really shouldn’t be left outside on his own in the immediate future, whereas that should have been completely flagged” (P5).

This caregiver was annoyed because this information should have been given as a matter of urgency and not just by chance. But when she did have the meeting with the OT she was happy with the information:

“The OT gave me a good bit of information now about his eyes, and am, you know about what the condition is and really that there’s no hope of it getting better” (P5).

Members of one family were upset because they were expecting a meeting with the discharge co-ordinator to discuss all the options but this never materialised she said:

“We were told that we’d have a discharge person, who would bring us in for a meeting, and they would discuss all the options with us and they would tell us where to go. But like did we meet that discharge person, no, not at all” (P4).

One caregiver’s relative was prescribed new medication and on probing as to whether someone went through the new medication with them:

“No Ahh no, well you see I presume we will get that here now on Monday when she’s going home” (P6).

Another caregiver did get some information but on probing it seems like she was still not sure, especially about the medications:

“They did change the medications ya....Well she just kind of showed it to us really...Hopefully I will manage...” (P7).

On asking another caregiver whether she got any information on the medications she said:

“No, no. Only to get the prescription and I got it yesterday. No and some of them are changed ya” (P9).

Uncertainty was an issue for caregivers around information received.

#### **4.6.2 Uncertainty**

Caregivers were often unsure about who got what information. An absence of one key liaison person to give information to patient and families was notable. One caregiver whose relative had a planned admission said:

“I haven’t got anything now this time cause it was my sister was doing the discharge so she’s been told stuff and about the physio and things” (P8).

Even though this relative is the main caregiver the information was given to the person who collected their relative on the day of discharge. On asking another caregiver did she think information was given to anyone else as her relatives’ niece is possibly the next of kin in her documentation:

“I don’t know, I don’t think so” (P3).

One caregiver was asked whether the information may have been given to her hospitalised relative. This caregiver was worried that this was possible and her mother is deaf so may have missed something important:

“They would have spoken to mother more than me, and to be honest she’s quite deaf so she wouldn’t have picked up.... she would have missed a lot as well you know...” (P7).

Three caregivers mentioned they received a letter for their GP outlining discharge information.

In summary caregiver’s experience of receiving adequate information and knowledge varied. Only two caregivers out of the nine interviewed were happy about the amount of information received prior to hospital discharge and these caregivers were the only two to feel knowledgeable enough to cope with their older adult relative after going home. While some information was given to all of the caregivers they felt it was not enough and some relatives had new medications that were not fully explained. Overall, communication of discharge information to caregivers was inconsistent and fragmented. Throughout the interviews there was a sense of ‘wanting to do what’s best’ during the older adult’s hospitalisation, throughout the hospital discharge and at home after discharge.

#### **4.7 Wanting to do what’s best**

‘Wanting to do what’s best’ became apparent throughout the data analysis. This was explicit in both the physical and psychological categories and it is more implicit in the other categories. Language suggests that caregivers put themselves second, with little consideration of the consequences to their own health, especially in the short term for

participants “would do anything” for their relative despite feeling under pressure and having too much to do.

One daughter explained:

“Well it’s hard going now at times definitely cause we’d be trying to do what’s best for Mam as well” (P8).

Another daughter expressed:

“Like we’re fine. We’re trying to do what’s best for Mum” (P4).

While all caregivers in the current study may not have articulated that they wanted to do what’s best, it was inherent in their stories. One daughter who works on a busy farm dropped everything to help her mother saying:

“My brother rang me in the morning like and I was at home feeding a calf like and here he is on the phone...“you’ll have to come down”...I was there... get rid of the calf and go down” (P3).

A distant relative cared enough to help her relative even though she worked and also helped care for another family member:

“Well I suppose twas landed on me d’you know that kind of a way. But as I say I work and then d’you know...I have a brother who’s handicapped, well he’s with care like but I bring him out every couple of weeks as well like and but what can you do like? You can’t just let a person, you know” (P4).

One daughter shares the caregiving with her sisters. However, they all work so they have a formal caregiver to help also, making sure that their mother is always looked after, she explained:

“we all...we have somebody that we pay privately to come in during the day, we also have day care 2 days a week who are absolutely fantastic I have to say. And then we all have rotas every single night and Saturdays and Sundays” (P4).

Despite one caregiver recovering from breast cancer she will also do what is necessary to help her dad:

“You see it’s his periphery vision so when he’s walking he can’t ... like they said it’s not unmanageable but he will need a lot of...” (P5).

Another daughter who has been looking after her mother (who has a diagnosis of Parkinson’s disease), for three years, twenty-four hours a day, went on to explain:

“No. But sure nobody can picture themselves doing it, they fall into place. You fall into the role....Sure you just have to do it and that’s it” (P6).

In summary, while the findings are presented under the four attributes of readiness for hospital discharge, ‘wanting to do what’s best’ emerged as an overarching category. While ‘wanting to do what’s best’ was articulated by only two of the caregivers, it was apparent in all of their stories and actions. Some caregivers dropped their work or whatever they were doing in the immediacy of the illness while some were doing their best for three years or more. Whether caregivers were ready or not, physically and psychologically, for the older adult’s discharge from hospital, they did their best whether they had adequate support or information.

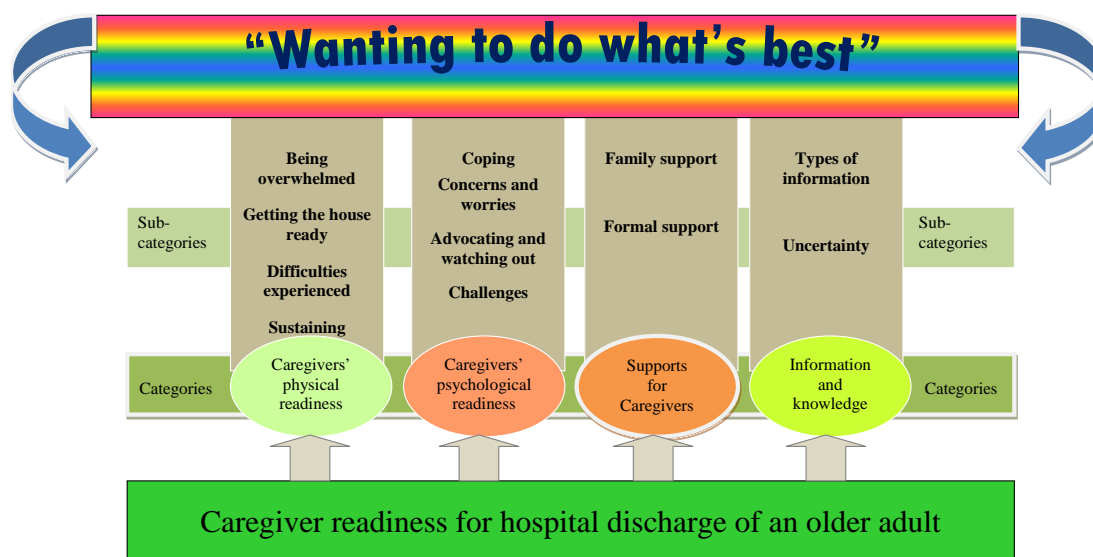
## **Summary**

In exploring caregiver readiness for the hospital discharge of the older adult within 24 hours of discharge, findings were presented under the four attributes of readiness for



hospital discharge (Galvin *et al.* 2017): Caregivers' Physical Readiness, Caregivers' Psychological Readiness, Supports required by Caregivers and Information required by Caregivers. An overarching category of 'wanting to do what's best' also emerged (Figure 2).

**Figure 2. Readiness of caregivers**



Overall, the findings indicate that none of the caregivers in this study were ready to take the older adult home on the day of hospital discharge. Furthermore, there were differences between caregivers whose relatives were admitted for a planned admission or an emergency admission, with caregivers of those whose relatives admitted for emergency care faring poorer in all four attributes of readiness for discharge.

With regards to caregivers' physical readiness to care for the older adult after hospital discharge, all of the caregivers wanted to do what is best for their relative but some caregivers declared that they were overwhelmed, that caregiving was 'difficult' and 'tough going'. Caregivers explained that they 'fell into the role' or 'it was landed' on them. But regardless of how ready they were to take their relative home from hospital they just 'got on with it' or were 'happy to do it'. Caregivers cleaned, renovated and

prepared the house as this assisted them in getting ready. Caregivers mentioned difficulties experienced. They found their relatives could be un-cooperative and the discharge from hospital put extra pressure on caregivers. Caregivers also declared they did not know how they would physically sustain the level of caregiving required, in the long term.

Caregivers were not asked if they felt psychologically or emotionally ready to take their older adult home from hospital at any time during the hospital stay. Caregivers found it difficult to cope and had concerns and worries about the older adult and how they would manage caregiving. Again, caregivers again wanted to do the best they could for the older adult and this included advocating before, during and after their relatives' hospital stay. However, caregivers had challenges and declared that their relative would 'try your patience' especially those relatives who had emergency admissions. During this difficult time any 'fissure and cracks' in relationships emerged within their families.

Supports required by caregivers to take the older adult home from hospital had two distinct categories; formal and informal support. Informal support was in the form of other family members and friends and all these caregivers had help from family members with some declaring they were 'balancing out' the care between them and others by devising rotas. Formal supports such as convalescence, PHN and GP varied and the offer of these supports to caregivers was inconsistent. Some caregivers 'had to ask' for formal supports such as convalescence and some declared they had to keep 'pushing and pushing'. The offer of formal supports meant that caregivers could 'take a breath now'. When caregivers were asked if they were ready to go home without the support of convalescence they indicated they would have 'tried to manage' or that they would have had 'no other choice'.

Information required by caregivers varied with only two caregivers out of the nine interviewed being happy with information given prior to hospital discharge. These were the only two to feel knowledgeable enough to cope with the older adult after going home. While some information was given to all of the caregivers they felt it was not enough and some caregivers did not have enough information about the older adult's medication. This stemmed from the different types of information required including information on diagnoses and medication management. In addition, caregivers required information about supports available and how to negotiate the health system for their varying requirements.

Uncertainty was common, because communication of discharge information to caregivers was inconsistent and fragmented within the areas of information about convalescence, illness and diagnoses and some caregivers were not sure which family member got what information. There were inconsistencies in PHN referrals with caregivers unsure whether they would have ongoing PHN involvement.

Overall, findings indicate that even when caregivers are not ready they will still look after their relative to the best of their ability because they 'want to do what's best'. Some caregivers were explicit in 'wanting to do what's best' while it was implicit in the other caregiver's stories. In the current study, all of the caregivers were willing to take on the extra workload in the short term but were unsure of their ability to sustain the necessary level of care giving in the long term. The next chapter discusses these findings in the context of the relative literature.

## **Chapter 5 – Discussion**

### **Introduction**

In this chapter a discussion of the findings in the context of the relevant literature will be presented. A discussion on the strengths and limitations of the study follows, concluding with recommendations for practice, education and research. The chapter begins with a discussion on demographics. Caregiver readiness for the hospital discharge of an older adult is then discussed under the attributes of readiness for hospital discharge (Galvin *et al.* 2017) i.e.: Caregivers' physical readiness, Caregivers' psychological readiness, Support for caregivers and Information and knowledge. A discussion on the final category "Wanting to do what's best" is also included.

### **5.1 Demographics**

In the current study, the caregiver interviewed was someone who was identified by the patient as the person who would offer support post discharge as per previous studies (Boughton and Halliday 2009, Perry and Middleton 2011, Gustafsson and Bootle 2013, Neiterman *et al.* 2015). Caregiver age ranged from 30-79 years with the majority aged between 40-59 years. This is similar to the results from the census 2011 (Family Carers Ireland 2017) and other countries (Arnsberger *et al.* 2012). A table summarising demographics is available in Appendix 23.

All of the caregivers interviewed were female. Initially, the researcher thought that this would cause gender bias and male caregivers were approached but they referred the researcher back to a female caregiver, in fact one said "he was only waiting until his sister got here". The predominance of females as the primary caregiver is a similar phenomenon globally (Shyu *et al.* 2010, Fitzgerald *et al.* 2011, Perry and Middleton

2011, Arnsberger *et al.* 2012, Young *et al.* 2014, Knier *et al.* 2015, Neiterman *et al.* 2015, Rustad *et al.* 2017). While men contribute to caregiving, it is usually in a more gender specific fashion such as assisting with DIY or the garden (Arnsberger *et al.* 2012, Kruijswijk *et al.* 2015, Wolff *et al.* 2017).

All caregivers had some help from other family members except for one; this is common across Ireland, Europe and America with varying degrees of assistance provided from siblings depending on the size and gender makeup of the family (Kruijswijk *et al.* 2015). Two of the caregivers in this study had other non-paid caregiving responsibilities and Arnsberger *et al.* (2012) found this to be the case in Northern Ireland in their international study, but not in China or the US. In this study, all caregivers were engaged in paid employment except one who was retired, again similar to Arnsberger *et al.*'s (2012) findings amongst caregivers in Northern Ireland.

In relation to education, Perry and Middleton (2011) found no correlation between education status and level of knowledge about caregiving but female caregivers reported a higher sense of competence. To achieve transferability and generalisability caregiver level of education is reported in the current study. Apart from one caregiver who finished her education at second level, all of the caregivers had some higher level education ranging from Fetac level course to Master's Degree, indicating a diversely educated sample.

## **5.2 Caregivers' physical readiness**

To be ready to care for the older adult at home post hospital discharge, caregivers need to be physically stable. Caregivers' physical stability is their perceived physical readiness to take the older adult home from hospital as, being in a good physical condition as "felt" by the caregiver (Galvin *et al.* 2017). Findings from the nine semi-

structured interviews with caregivers indicate that prior to hospital discharge none of the caregivers were asked about their physical ability to care for the older adult.

Therefore, caregivers were asked by the researcher if they were physically ready for hospital discharge of the older adult and the findings indicated that caregivers in the current study were physically overwhelmed by hospital discharge. This is a problem for caregivers around the world (Gustafsson and Bootle 2013, Young *et al.* 2014, Coleman and Roman 2015). In Ireland, 38% of caregivers looking after someone at home reported feeling completely overwhelmed by their caregiving responsibilities (Care Alliance Ireland 2013). In, addition, studies indicate that caregivers are not physically assessed to take their relatives home after a period of hospitalisation and they feel that their physical limitations are not recognised by healthcare providers (Fitzgerald *et al.* 2011, Perry and Middleton 2011, Gustafsson and Bootle 2013, Young *et al.* 2014, Ågård *et al.* 2015, Coleman and Roman 2015, Rustad *et al.* 2017).

There are many reasons as to why caregivers are overwhelmed hospital discharge of an older adult. Caregivers in the current study were caregiving for their older relative to some extent prior to this hospital admission; however, caregiving had now become more intense. Caregivers explained that caregiving is physically demanding for them and they are exhausted. Erratic provision of formal support was another such reason in the current study, with studies in the US (Knier *et al.* 2015), and in Denmark (Ågård *et al.* 2015) having similar findings. In addition, caregivers in the current study were overwhelmed because of short notice of hospital discharge and this compares to findings in an international study (Hesselink *et al.* 2012). Other studies reported contributing factors such as tiredness, managing medication and having a lack of time to prepare the home for their relatives (Fitzgerald *et al.* 2011, Ågård *et al.* 2015,

Coleman and Roman 2015). These findings give insight as to why caregivers are overwhelmed by the hospital discharge of an older adult.

Caregivers balance multiple tasks during their older relatives' care transitions (Rustad *et al.* 2017). This study indicated that caregivers were happy to 'clean and renovate' the house as this assists caregivers to feel physically ready to bring their relative home. There was a sense of putting everything back together and making the place nice. Gustafsson and Bootle (2013) and Fitzgerald *et al.* (2011) reported similar findings.

Home modification or renovation is emerging as an important intermediary intervention to maintain older adults live independently at home for longer. Home modification has been found to enable older adults to live outside of long term institutionalised care for an extra 5-10 years (Kim *et al.* 2014). With regards to benefiting caregivers, home modification and renovation helped them to cope with their ageing relatives and their increasing care needs (Kim *et al.* 2014). These findings are echoed in the current study, caregivers cleaned and renovated and modified the home if necessary in order to keep the older adult living independently in their own homes for as long as possible. Caregivers do this because they 'want to do what's best' for the older adult but perhaps they also do this for themselves because sustaining the older adult's independence eases the burden of caregiving.

Findings demonstrate that caregivers in the current study experienced physical difficulties due to ill-health. One of the caregivers was particularly upset that she was not asked about her physical status as she was going through breast cancer. She was her father's main caregiver and was struggling at the time of hospital discharge. Allen *et al.* (2018) confirm that caregivers struggled to provide physical support to their relatives after hospital discharge due to their own health problems and this contributed

to re-admissions of the older adult to hospital. Young *et al.* (2014) indicated that caregivers should have their physical ability assessed as currently caregivers are not physically assessed to identify if they are ready to take an older adult home.

Caregivers in this study experienced further difficulties during the discharge process because while feeling intense pressure to get organised and prepared for the hospital discharge, caregivers found their relatives to be 'uncooperative' and caregiving could be 'tough going'. In Japan, Honda *et al.* (2014) indicated that uncooperative care recipients increased caregiver burden.

Caregivers in the current study indicated they could not have the older adult live with them, especially in the long term because this living situation caused issues with other family members and sometimes the older adult criticised their lifestyle. Chong *et al.* (2017) confirms that caregiver distress increases if the older relative lived with the caregiver but having outside or paid assistants was found to decrease caregiver distress. However, apart from one who had home help, none of the caregivers in this study had outside or paid assistants. However, some did share tasks with siblings with some devising rotas for the near future.

Caregivers worried about their own health and the ability to sustain this level of caregiving into the future (Gustafsson and Bootle 2013). From the health care providers point of view, nurses understand that patients will need physical help at home and in fact Weiss *et al.* (2014) found that nurses rated the necessity of physical help at home higher than patients did. Patients are happy to receive this help from their caregivers but caregivers are worried about being able to sustain this level of caregiving from a physical perspective (Gustafsson and Bootle 2013).



In the current study caregivers worry about sustaining the current level of care that they were providing because they found caregiving ‘tough going’. Perry and Middleton (2011) confirm that this is an important finding as their study indicated that caregiver burden increased at three months, suggesting that caregiving gets more difficult to sustain as time goes on. Caregivers in Gustafsson and Bootle's (2013) study considered supports and services to be an essential component of helping caregivers sustain their ability to care into the future.

Interestingly, Ågård *et al.* (2015) established that caregivers reported positive feelings when they were able to provide effective and sustainable solutions to the challenges they faced suggesting that caregivers want to care for the older adult but require help to deal with the many challenges that arise. In a recent RCT, Toye *et al.* (2016) tentatively suggest that the improvement in the preparedness of caregivers was sustained beyond the one-month period because ongoing links with support sources had been initiated. This adds strength to the point that caregivers may be able to sustain caregiving if they have the necessary supports in place.

### **5. 3 Caregivers’ psychological readiness**

Caregivers need to be psychologically able to care for the older adult post hospital discharge, in order to feel ready to take them home. The attribute of psychological ability includes the ability to cope and retain control (Carroll & Dowling 2007, Bobay *et al.* 2010) and the confidence to manage the hospital discharge (Galvin *et al.* 2017). Caregivers were therefore asked by the researcher, if they perceived they had the psychological ability to cope with the hospital discharge of the older adult.

A key finding in the current study is that caregivers are not able to cope because they are uncertain and stressed about the hospital discharge of the older adult. A previous

study in Denmark indicated that caregivers also struggled to cope (Ågård *et al.* 2015). Caregivers in other studies have described the hospital discharge of the older adult as chaotic, confusing, frustrating, difficult, traumatic or as a time of crisis (Boughton and Halliday 2009, Fitzgerald *et al.* 2011, Young *et al.* 2014, Neiterman *et al.* 2015). In addition, Coleman and Roman (2015) indicated that caregivers in their study were not confident.

Even though caregivers find it difficult to cope, getting prepared for life at home is identified as the main concern of all involved (Rydeman and Törnkvist 2010) and this came to the fore in the current study. Caregivers prepared the home, they devised caregiving rotas and they made sure there was food in the fridge but they remained unsure if they would cope with the transition. Toye *et al.* (2016) indicated that caregivers who received an extra support program had decreased strain and stress indicating that caregivers require more preparation to help them to cope during the hospital discharge of their older relative.

Support and psychological wellbeing or coping seem inter linked because those caregivers in the current study who had any form of professional support felt more able to cope. Similarly, Rodríguez-Pérez *et al.* (2017) discovered socially-supported coping strategies were associated with a superior quality of life in caregivers of cancer patients and Kiral *et al.* (2017) established that support can play a significant role in alleviating caregiver depression. According to Verbakel *et al.* (2016) support is the main element preventing the negative consequences of informal caregiving.

It is clear from the findings of the current study that caregivers were concerned and worried about the older adult's physical and mental health as well as managing their activities of daily living. Similarly, caregivers in Australia raised concerns about daily

tasks (Gustafsson and Bootle 2013) as did caregivers in the US (Young *et al.* 2014). Caregivers in Sweden were also concerned about the older person's state of health (Rydeman and Törnkvist 2010). Ågård *et al.* (2015) and Rustad *et al.* (2017) indicated that vast responsibilities of care lead to unnecessary concerns and worries. Mostly caregivers worried about not knowing how they would manage at home (Rydeman and Törnkvist 2010) and this encapsulates what caregivers were worried about in the current study.

A fundamental reason as to why participants in the current study were worried was that they did not receive enough information. Likewise, caregivers in Australia indicated that if they had good quality information they would not have been so concerned (Boughton and Halliday 2009, Perry and Middleton 2011). With caregivers in the US and Denmark also harbouring concerns related to information (Young *et al.* 2014, Ågård *et al.* 2015). Bolstering this point, Boughton and Halliday (2009) and Rustad *et al.* (2017) surmised that adequate information prior to discharge may have minimised many caregiver concerns.

Caregivers in the current study were concerned because they worried about their own health. There were similar findings in Australia (Perry and Middleton 2011, Gustafsson and Bootle 2013). In addition, a home health therapist the US was so concerned about the mental health of one caregiver that he insisted that the caregiver go to her doctor (Young *et al.* 2014). However caregivers put themselves second through this difficult time because they ensured that their relative got the best care possible and took care of their relative's finances. Ågård *et al.* (2015) indicate that advocating is one of the main dimensions of caregiving. Rustad *et al.* (2017) indicated that caregivers in their study also took responsibility for the older relative during hospital discharge. However, in the current study advocating and watching out for the

patient required time and perseverance, with caregivers in Ågård *et al.*'s (2015) study having similar experiences. Spouses in Denmark mainly advocated to promote progress in the patient's recovery (Ågård *et al.* 2015). This is comparable to findings in the current study with caregivers spending time in the hospital everyday ensuring the older adult got the best care possible.

In watching out for their relative, caregivers repeatedly had to ask for HCP's for assistance to ensure care was given to the older adult. Unfortunately, similar to findings in a US study, caregivers in the current study sensed that their asking HCP's for assistance triggered annoyance amongst healthcare professionals (Coleman and Roman 2015). Mitchell *et al.* (2018) indicated that caregivers in their study expressed doubt and mistrust of the HCPs causing caregivers to step in to advocate on the patient's behalf. In addition, spouses in Denmark worried whether patients would receive the necessary attention and care (Ågård *et al.* 2015). This is evident in the present study where caregivers had to continuously advocate ensuring that their relatives were given the correct medical treatment, that they were properly cared for and that they were not sent home until they were well enough.

Challenges were mentioned by many caregivers. Caregivers indicated that while they are willing and want to care for their older relative, their relative would 'try your patience'. Similarly caregivers in another study stated they had a love-hate relationship with the caregiving situation due to changed personality, roles and relationships (Perry and Middleton 2011). Caregivers in Fitzgerald *et al.* (2011) study indicated that they felt life was different now. Rustad *et al.* (2017) echoed these findings but also add that hospital discharge is a challenge for all involved including the caregiver, patient and the healthcare provider.

Caregivers in the current study encouraged their relatives to do as much as they could for themselves because they did not want helplessness or dependence to set in. Unfortunately, relatives were sometimes not amenable to their caregiver's suggestions such as having someone to come in to the older adult's home to help them with daily tasks. This is similar to caregivers in the US who indicated difficulty retaining control of the situation (Schwartz *et al.* 2019). A tentative explanation for these challenges could be that the older adult is also having a difficult time adjusting to the situation. This was apparent in Australia as patients described frustrations that they faced after coming home such as not being able to 'do' for themselves (Gustafsson and Bootle 2013).

Caregivers in the current study were happy to care for their relative but discharge of the older adult from hospital brought an added pressure to their already busy lives. Caregivers in Denmark reported many challenges such as balancing the needs of the patient, family, children and employment but on a positive note described rewarding feelings if they found solutions to the many challenges (Ågård *et al.* 2015). Caregivers in Norway found helping their older relative to regain a level of self-management meant making changes in their family lives (Rustad *et al.* 2017). Similarly caregivers in the current study had to devise rotas and increase the amount of time spent caregiving to deal with the challenges faced along the way.

Caregivers in the current study reported that they were sad that their relative's recent illness and hospitalisation had caused a loss in their relative's independence. As a consequence, mental health issues came to the fore because of the added pressure, the extra responsibility, put on caregivers. Importantly, Arnsberger *et al.* (2012) indicated that caregiver's mental health status can be compromised as a result of caregiving. The pressure of getting ready for the hospital discharge of the older adult brought out the

‘fissures and cracks’ in one family. Previous studies indicate caregiving post hospital discharge has an impact on the whole family suggesting that caregiving in general is stressful and caring for an older adult is particularly stressful (Boughton and Halliday 2009, Fitzgerald *et al.* 2011, Ågård *et al.* 2015, Penning and Wu 2015). Provision of care for an older parent has a more negative impact on the caregiver and adult child caregivers experience the burden of role reversal (Penning and Wu 2015). Furthermore, caregiving for a parent poses contradictions due to role reversal and relationships with other family members and those family members who show hesitancy to care cause difficulties within the family (Penning and Wu 2015). This echoes the sentiments expressed by one participant in the current study on the effect of the hospital discharge of the older adult on family relationships.

Navigating the health system for support was challenging for caregivers in the current study and Young *et al.* (2014) concur. Caregivers in the current study were exhausted. Similarly caregivers in the US had interruptions to sleep and giving assistance non-stop twenty-four hours a day posed a significant challenge (Young *et al.* 2014). Young *et al.* (2014) suggest that acknowledging these challenges in conjunction with caregivers could alleviate some of the many problems that arise when caring for an older adult after discharge.

#### **5.4 Supports for caregivers**

Support is an attribute of readiness (Galvin *et al.* 2017) and caregivers require formal and informal/family support to feel ready for the hospital discharge of an older adult. All of the caregivers in this study had family support but availability of formal supports were fragmented and inconsistent. According to Care Alliance Ireland (2013) caregivers require a health and social care system that supports them in this vital role.

At present in Ireland the formal support system comes from hospital staff, the PHN, and GP.

Lack of family support is a barrier to discharge readiness (Coffey and McCarthy 2013). Fortunately, all the caregivers in this study had family support. In a Danish study only one caregiver out of eighteen was offered formal support, comparatively the rest relied on family and friends (Ågård *et al.* 2015). This highlights the importance of family support. Be that as it may, in some cases, caregivers have little family support available to them once they have been discharged (Boughton and Halliday 2009).

Having family support decreases the caregiving burden (Arnsberger *et al.* 2012) and caregivers in the current study indicated that they were ‘balancing it out’ with the rest of their family. Studies have shown that balancing the needs of the patient, family, children and employment is stressful (Perry and Middleton 2011, Ågård *et al.* 2015). Caregivers reported the effect of their older relative’s illness on themselves, their children, the wider family circle and social network (Perry and Middleton 2011, Gustafsson and Bootle 2013, Rustad *et al.* 2017).

At present in Ireland, it seems family caregivers receive the bulk of help and support from other family members but family structures are changing. Factors such as caregivers’ geographic proximity to their relatives around the world has become a new issue (Wolff *et al.* 2017). This is perhaps one such change that is going to cause problems to families sharing the burden of caring for their older relatives, especially in unexpected situations such as after an unplanned hospital admission.

Caregivers require formal support to manage hospital discharge of their relative (Fitzgerald *et al.* 2011, Family Carers Ireland 2018). Knier *et al.* (2015) reported that

caregivers who do not receive specific targeted support are overwhelmed by the discharge experience. In this study, apart from the period of convalescence, formal supports offered to caregivers was erratic and as already highlighted, this was one of the reasons that caregivers reported feeling overwhelmed. Similarly, caregivers in Australia also perceived support services during home recovery were deficient with caregivers believing they would receive little if any follow up or support from the health care system, thus exacerbating their worries (Boughton and Halliday 2009, Fitzgerald *et al.* 2011). In addition, continuity and co-ordination between hospitals and community services were poor (Boughton and Halliday 2009, Fitzgerald *et al.* 2011, Gustafsson and Bootle 2013).

Caregivers were upset if they were not offered services to which they were entitled. These supports would have assisted them with the traumatic experience of hospital discharge. Studies from Australia (Gustafsson and Bootle 2013) and the US (Young *et al.* 2014) reported a similar experience amongst caregivers where little information was offered on supports available causing caregivers to be upset, as they needed that extra support. Rustad *et al.* (2017) indicated that nurses should recognise caregiver needs and offer the necessary support. Supporting caregiver needs might positively influence their readiness to care for the older adult after discharge and identifying proper strategies for support are important for diminishing unnecessary worries and concerns among caregivers (Rustad *et al.* 2017). However, Rydeman and Törnkvist (2010) indicated that health care professionals could exclude caregivers and the older persons by being authoritarian and thereby deny them all support (Rydeman and Törnkvist 2010).

Family Carers Ireland (2017) indicate that their second national goal is to provide support to caregivers to manage their physical, mental and emotional wellbeing but



unfortunately caregivers in this study perceived that they were not given the support they required to take the older adult home. Attributes of support are both psychological and physical (Collins 2014) but caregivers in this study did not appear to know what supports are available to them. Knowing what support is available positively reinforces readiness for hospital discharge (Galvin *et al.* 2017). Nonetheless, caregivers in the current study were upset because of the lack of information regarding formal support available.

Similarly Neiterman *et al.* (2015) reported that lack of familiarity with community services was emotionally and physically draining for caregivers. Toye *et al.* (2016) reported that caregivers spent a large amount of time navigating the healthcare system to get supports, while some of the caregivers in the current study were given information on supports simply by chance. Internationally caregivers report lack of options to assist them during the post hospitalisation recovery period (Arnsberger *et al.* 2012). This is similar to findings in the current study where caregivers stated that they have ‘no other choice’ even though they are not ready to take the older adult home, they are just ‘trying to manage’ caring for the older adult.

Coffey and McCarthy (2013) indicated the PHN as a valuable source of support post discharge but only four of the caregivers and patients in this study had their PHN involved in their care prior to their original hospital admission and the remainder did not know if they would receive a visit from the PHN after going home. Telling caregivers that they will have a call from the PHN could assist with supporting the caregiver through what most describe as a difficult time. However, Dunnion and Kelly (2008) and Coffey and McCarthy (2013) have found levels of referral to be unsatisfactory with 74% of PHN’S never notified of an ED visit or hospital admissions

of older adults and it is unknown whether any or all of the PHN's associated with this study were notified of the older adults' hospital admission.

This study found an inconsistency in the offer of convalescence. Caregivers whose relative had a planned admission were offered convalescence as a matter of routine. However, those caregivers whose relatives had unplanned or emergency admissions were not routinely offered a period of convalescence, they had to ask for it and this was upsetting. This is echoed in other studies in Australia (Gustafsson and Bootle 2013) and Denmark (Ågård *et al.* 2015) where caregivers who did not receive formal supports were upset.

This study reported that caregiving is also financially draining as some caregivers had to take significant time out from paid employment to care for their relative. Wolff *et al.* (2017) indicated that caregiving and paid employment are competing responsibilities in a caregiver's everyday life. Just as caregivers in the current study have pointed out, Wolff *et al.* (2017) indicate caregiving has emotional and financial consequences for caregivers. Internationally, caregivers report similar feelings, with trying to balance the demands of family, employment and caregiving (Arnsberger *et al.* 2012).

Caregivers require more formal support to acquire the necessary skills in navigating the health care and social systems (Ågård *et al.* 2015), this was also apparent in the current study because caregivers asked for extra help and support. However, caregiver needs are overlooked because the caregiver is typically viewed as a resource for the patient, rather than someone who needs support and assistance (Young *et al.* 2014). Caregivers in the current study wanted to be involved in the older adults care but struggled to be included.

Positively, an RCT providing extra supports to caregivers after discharge sustained improvements in preparedness to take the older adult home beyond one-month (Toye *et al.* 2016). Importantly, the support needs identified could all be met within the context of existing resources (Toye *et al.* 2016). Another study indicated that a good or poor experience of going home was related to support received from therapy services, which were considered an essential component of sustaining caregiver ability to care into the future (Gustafsson and Bootle 2013). Mitchell *et al.* (2018) discovered three criteria that caregivers and patients require from support services i.e. they want to feel cared for and cared about by medical providers, they want to have accountability from the health care system, and they want to feel prepared and capable of implementing care plans.

In addition, to amplify caregiver problems with formal support in the current study, some of the older relatives refused help and supports from services without discussing this with their caregiver. Caregivers found this problematic as the caregivers were the ones who needed extra supports to maintain the level of time and effort required to juggle all of their responsibilities. Mitchell *et al.* (2018) also reported how the patient declined offers for a visiting nurse to assist with care at home, preferring instead that their caregiver perform those tasks. From the relative's perspective their preference was related to personal comfort, dignity, or to avoid having strangers in the house. Perhaps inclusion of the caregiver during discussion and communication of supports would assist in all stake-holders in the situation having their say.

## **5.5 Information and knowledge**

Caregivers require adequate information and knowledge to feel ready for the hospital discharge of the older adult (Galvin *et al.* 2017). On asking caregivers what

information they were given by the healthcare provider there were marked differences between those whose relative had an emergency admission and those whose relative had a planned admission. On asking caregivers if they thought the HCP had given the caregivers enough information to go home, some were happy and felt they had been given everything they needed but some were not. This is a global problem with caregivers in other studies also citing receiving insufficient information (Boughton and Halliday 2009, Fitzgerald *et al.* 2011, Hesselink *et al.* 2012, Toye *et al.* 2016, Rustad *et al.* 2017, Schwartz *et al.* 2019).

A crucial finding in the current study was that none of the caregivers were offered an in-depth discussion or written instructions prior to discharge. Information is necessary to respond to common problems in the post discharge period (Mabire *et al.* 2015). Balaban *et al.* (2008) recommend a formal communication plan, to ensure that everyone is informed of all the details involved in discharge, including written information or instructions. Therefore, it may be argued that lack of information could be one of the reasons that caregivers are overwhelmed. Bobay *et al.* (2010) seem to concur with this view because they established that information was highly associated with how much patients felt they could cope (Bobay *et al.* 2010).

Information about resources, knowledge of their home-going needs and medications are indicated as the most important items of information necessary to feel ready to go home from hospital (Anthony and Hudson-Barr 2004). However, caregivers in the current study did not receive these components of information. While participants expected the HCP's to share this information with them during the hospital stay, this did not always occur. Hesselink *et al.* (2012) indicate that information is provided, but there appears to be no organised time of family discussion, and that the HCP's indicate lack of time as a reason for this.

Caregivers who admitted to feeling concern and apprehension indicated that if they had good quality information they would not have been so concerned (Boughton and Halliday 2009). Caregivers in Rydeman and Törnkvist's (2010) study agreed that when they had adequate information and time to make arrangements they felt prepared for life at home after discharge. Caregivers have specified the 'family conference' as a crucial opportunity for communication and discussion of all issues prior to discharge (Rydeman and Törnkvist 2010, Gustafsson and Bootle 2013). In Ireland, this is usually in the form of a meeting with the discharge nurse-coordinator and some of the multidisciplinary team. Caregivers in this study wanted to meet with the discharge nurse-coordinator to plan the transition but none received that meeting even though some of their relatives were hospitalised for up to three weeks prior to discharge.

Studies indicated that caregivers are of the view that having one person to liaise with, to ask questions about various aspects of care (from bandages, medication, entitlements and mostly to tell them that what they are doing is right) would be most helpful throughout the discharge transition (Rydeman and Törnkvist 2010, Coleman and Roman 2015). Caregivers in this current study expected that they would get assistance in some of these areas from the discharge co-ordinator. However, a meeting did not materialise for any of the caregivers thus leaving them unprepared.

Another key issue found in the current study is that information provided regarding the time of hospital discharge of the older adult was erratic with most only getting one day's notice. There were similar findings in Australia (Fitzgerald *et al.* 2011, Allen *et al.* 2018) with caregivers perceiving erratic or late notice of discharge to be unsafe (Allen *et al.* 2017). Caregivers in this study were upset because they need time to organise transport to the convalescence home, with some caregivers taking time out from paid employment to collect the older adult from hospital.

Only one caregiver in the current study reported getting information regarding their relative's medication and likewise caregivers reported being overwhelmed by medication management in the US (Coleman and Roman 2015). Schwartz *et al.* (2019) were concerned about the potential for negative patient outcomes related to communication issues, particularly those associated with medication use. Similarly, caregivers got very little to no information about procedures that took place during their relatives hospital stay. Family Carers Ireland (2017) third national goal implies that, provision of adequate information and training to caregivers has improved. However, it is apparent in the current study that caregivers of older adults did not receive adequate information prior to hospital discharge concurring with other studies (Boughton and Halliday 2009, Fitzgerald *et al.* 2011, Young *et al.* 2014, Toye *et al.* 2016, Rustad *et al.* 2017, Schwartz *et al.* 2019).

Allen *et al.* (2018) profess that when patients are too unwell to seek information about medication changes, their caregivers want to know this information on their behalf. Coleman and Roman (2015) indicated that caregivers want to be included in decision making. Similarly, caregivers in the current study want to be involved in the care and discharge planning of their relative. Family Carers Ireland (2017) recognises the value and contribution of caregivers and promotes their inclusion in decisions relating to the person they care for and progress in this area has been reported. Unfortunately, caregivers in the current study perceived that plans were made without any input from them. This is not dissimilar to findings in other countries (Fitzgerald *et al.* 2011, Coleman and Roman 2015, Rustad *et al.* 2017, Schwartz *et al.* 2019) where caregivers are not given information on behalf of the older adult to assist them in being ready for discharge.

Improved patient-clinician and inter-professional communication is known to be positively associated with a person's perception of readiness for discharge (Anthony and Hudson-Barr 2004, Weiss and Piacentine 2006, Bobay *et al.* 2010). Toye *et al.* (2016) indicated that a reason for the provision and communication of poor discharge information is limited time for the hospital staff to liaise with caregivers prior to hospital discharge. However, some of the relatives were in hospital for three weeks in the current study and this still did not impact on the information received by their caregivers. Regarding information given by HCP's, Connolly *et al.* (2010) indicate poor staffing levels prohibiting time for proficient communication with patients and their families.

Overall, information given to caregivers in the current study was fragmented. Similarly caregivers in the current study were unaware as to whether their older adult relative received any of the required information. It appears that there was no standardised time or procedure for giving discharge information to families/caregivers or patients in the current study. Similarly, Hesselink *et al.* (2012) indicated that discharge information was given irregularly, consequently patients, especially the older adult, were often unaware of the importance of the information provided.

In balancing their older relatives' autonomy, caregivers struggled with their own need for information (Rustad *et al.* 2017). However, in Norway, next of kin are entitled by law to healthcare information with the patient's consent. Perhaps a lack of understanding, of the law on sharing patient information, by healthcare professionals, is a barrier to providing caregivers with adequate information in Ireland. Currently in Ireland, the situation regarding HCP's providing information about patients is that 'any disclosure must be with, and limited to, the authority provided by the patient. If this is not forthcoming, no information may be provided' (MPS 2015). This has

implications for all involved. A consideration for the future could be, a discloser signed by the older adult and caregiver, this could take place during admission to hospital.

## **5.6 Wanting to do what's best**

Ready or not for the hospital discharge of an older adult, caregivers 'want to do what is best'. Wanting what is best for the patient is part of caregiving and this was clearly evident in the current study. In some areas wanting to do what's best was explicit as some caregivers articulated that they wanted what was best for their relative, but it was also apparent by their actions. They 'dropped tools', they devised 'rotas', they just 'got on with it', because they felt that they 'can't let them (the older adult) down'. Caregivers did everything they could to assist the patient throughout the discharge transition. Most were in the hospital every day, they prepared the house, and they collected their relatives' pensions and helped pay the bills. As this category appears to transcend the physical and psychological domains, it could be said that supports and information are facilitators to caregivers being ready and being able to do what's best for the patient.

Caregivers' 'doing what's best' is apparent in other studies. Caregivers balance the best level of health care for their older relatives between giving their older relative needed help with certain tasks, while encouraging the older adult to do for themselves so they could support their relatives' independence as long as possible (Rustad *et al.* 2017). While a study on caregivers of older adults with a diagnosis of cancer indicate the best thing that they could do for their loved one was to make sure that they enjoy every moment they can (Schwartz *et al.* 2019). This study also indicated that caregivers tried to figure out how to juggle all these things to the best of their ability.



Implicitly caregivers may not say they want to do their best but they certainly indicate they want to do the right thing. In one study caregivers worried about ‘doing’ a dressing right, with things such as, going to the chemist to buy cotton bandages and being met with an array of choices and all that is in their head is which is the best or right one to use (Boughton and Halliday 2009). Then there is what to do if the wound is red (Boughton and Halliday 2009). Similar to the current study the list goes on in the worry about doing the right or best thing. Caregivers found they did not have much time to be able to do many things for themselves, they sacrificed their own needs and even cut down hours of paid employment because of caregiving. This was a similar finding in Australia (Gustafsson and Bootle 2013). Caregivers in another study struggled to do the medication right and indicate they are not medical professionals and have to spend extra time checking and ensuring the right medication is given at the right time (Young *et al.* 2014).

Interestingly one caregiver in the US said that caregiving has nothing to do with love it has to do with reality (Young *et al.* 2014). Another caregiver voiced that she “will care for her husband until the day that she can no longer physically care” (Young *et al.* 2014). On the other hand, the older adults could see that the caregivers were encouraging and doing their best to assist them to further develop their independence (Gustafsson and Bootle 2013). So it seems that caregivers are doing their best in trying to work, care for the older adult, get ready for hospital discharge, manage their own family and do the right thing for everyone around them, but to what cost to their own health? Despite wanting to do what’s best, caregivers are not always physically or psychologically ready for the hospital discharge of their older adult and they do not always have adequate support or information and knowledge.

## Summary

In summary, in this chapter a discussion of the findings from the exploration of caregiver readiness for the hospital discharge of an older adult, within the context of the relevant literature was presented. The main finding is that caregivers are not ready for the hospital discharge of an older adult. This is the first study to use the attributes of readiness (Galvin *et al.* 2017) to guide data collection and analysis. In addition, this was the first study to interview caregivers within twenty-four hours of hospital discharge. While these are novel methods, there was much research to compare with.

Caregivers worldwide are not physically ready to take their older adult relative home and caregivers' physical ability is not assessed prior to discharge of their relative. Caregivers are physically overwhelmed and exhausted, they get ready by cleaning and preparing the house, they experience difficulties along the way and they cannot sustain this level of caregiving into the future.

Psychologically, caregivers do not feel ready to take their older adult relative home from hospital as they find it difficult to cope with the added responsibility and this has brought mental health issues to the fore in some instances. This concurs with the international literature. Caregivers have concerns and worries about the older adult, they continuously advocate and watch out but face many challenges along the way.

Caregivers require formal and informal supports in order to take their relative home and while all caregivers in this study had family or informal support and a period of convalescence, other formal supports as in PHN referral and financial supports were fragmented and inconsistent. This caused caregiver upset because caregivers need these supports to assist them physically and psychologically through this traumatic time. Internationally, the offer of formal support is also inconsistent with caregivers

finding it difficult to navigate the health care system to find the supports they require to be ready to take the older adult home from hospital. This is a key finding, as having adequate support is the main element preventing the negative consequences of informal caregiving.

Information given to caregivers was poor. None of the caregivers in this study were given written information or offered a meeting with their discharge nurse-coordinator. Caregivers across the world had similar experience indicating that lack of information causes further uncertainty since they do not have the necessary knowledge. Despite not feeling ready for the hospital discharge of the older adult, caregivers still ‘want to do what’s best’ and this was clearly evident physically and psychologically but it was also evident in wanting supports and information to help everyone through this difficult time.

In short, caregivers worldwide are not ready for the hospital discharge of an older adult, due to lack of preparation and lack of assessment by healthcare providers. This has implications for the caregiver as they are overwhelmed, worried and stressed during the discharge period. Older adults rely on their caregivers therefore, if caregivers are not ready to care for the older adult they return to the healthcare provider often resulting in readmission to hospital for the same illness. The next chapter provides an overall conclusion – which gives a brief overview of the study from background to discussion – followed by strengths, limitations and recommendations.

## Chapter 6 – Conclusion

### Conclusion

The aim of this study was to explore ‘caregiver readiness for hospital discharge of an older adult’. In order to carry out this exploratory study it was necessary to provide an operational definition of readiness for hospital discharge through a concept analysis outlined in chapter one. An integrated review of the literature on readiness for hospital discharge is presented in chapter two. Thirty-six studies were reviewed and the findings of the review were presented under three themes: Patient readiness for discharge, Healthcare provider’s practices in getting patients ready for discharge and Caregiver concerns and experiences of hospital discharge.

In chapter three the methodology for the study is detailed. A descriptive qualitative method and content analysis were deemed most suitable to address the aim of the study. Caregivers (n=9) of an older adult were interviewed within twenty-four hours of hospital discharge. Findings are presented in chapter four under the four attributes of hospital discharge: Caregivers’ physical readiness, Caregivers’ psychological readiness, Supports required by caregivers and Information and knowledge. An overarching category of ‘Wanting to do what’s best’ transcended the data. Findings are discussed in chapter five, followed by the conclusion which includes the strengths and limitations of the study. Finally recommendations are presented for practice, education and research.

Findings of the review indicate caregivers are critical to daily life and health of older adults for whom effective discharge planning is especially significant (Rodakowski *et al.* 2017). The integration of caregivers into the discharge planning process was found to reduce the risk of hospital readmission in older adults discharged to a community

setting (Rodakowski *et al.* 2017). However, caregivers are not routinely included in discharge planning. It is widely agreed that at home in the community is where we want to keep our older adults for as long as is healthy and safe (WHO 2015, Amalberti *et al.* 2018). This has implications for caregivers, who provide essential support to older adults however, the current study indicates that caregivers also need continued support.

No instrument exists to measure caregiver readiness for the hospital discharge of an older adult. Eleven studies were reviewed on caregiver concerns and experiences of hospital discharge and approximately half of these studies focused on caregivers of older adults. However, none of the participants were asked if they were ready for the hospital discharge of an older adult. No study used the attributes of readiness to guide the research question and none of the caregivers were interviewed within twenty-four hours of hospital discharge when experiences are foremost in their minds. Thus a study on caregiver readiness for hospital discharge of an older adult, where caregivers are interviewed within twenty-four hours of hospital discharge was warranted. In addition the attributes of readiness for discharge (Galvin *et al.* 2017) acted as a guide throughout.

Key findings in the current study indicate caregivers are not ready for the hospital discharge of an older adult, physically or psychologically. Caregivers are overwhelmed but they are willing to clean and renovate and get the house ready. However, caregivers experience difficulties and they cannot sustain this level of caregiving long-term. Caregivers find it difficult to cope with the hospital discharge, they have concerns and worries and challenges along the way but through all of this they continuously advocate for the older adult to ensure they got the best care.

Formal supports for caregivers were fragmented and inconsistent, referrals to the PHN and the GP were poor and caregivers found it difficult to navigate the health system. These findings concur with studies internationally.

Information given to caregivers was also fragmented and inconsistent. There were no written instructions given to any of the caregivers in the current study and this is common across the globe. Only two caregivers got information about medication management and none of the caregivers got to meet with a discharge nurse-coordinator. Discharge notice was also poor. These findings correlate with studies globally, as caregivers struggle with gathering adequate information about the older adult prior to discharge.

Findings of this study provide a unique account of the current state of caregiver readiness for the hospital discharge of an older adult. All four attributes of readiness for hospital discharge (Galvin *et al.* 2017) were explored with regards to the research question. While caregivers are not ready for the hospital discharge of an older adult it was unequivocally clear that caregivers 'want to do what's best'. The next section presents the strengths and limitations and this is followed by recommendations.

## **6.1 Strengths & Limitations**

The aim of the study was to explore caregiver readiness for the hospital discharge of an older adult within a twenty-four hour time frame. This was a unique feature, as this was the first time caregivers anywhere in the world were interviewed this close to hospital discharge. In addition, the chosen methodology achieved the aim of the study. A second strength of this study was the provision of an operational definition and attributes of readiness through a concept analysis (Galvin *et al.* 2017). These attributes provided a guide for the literature review, the semi-structured interview guide and data

analysis. The four domains of readiness for hospital discharge were used as a broad framework to present the findings. While this could be a potential limitation, however the researcher was mindful of not forcing the data to fit this framework. Regular meetings between the novice researcher and experienced faculty provided discussion and review of data collection and analysis and these meetings generated valuable guidance in considering other viewpoints and alternatives.

As with any study there were also limitations. A purposeful sample could be deemed a limitation as the sample is limited to those who are willing to partake but a purposeful sample was deemed appropriate to answer the research question in this study (Sandelowski 2000, Kim *et al.* 2017). It was aimed to have ten participants but only nine were available due to fewer discharges to the convalescent system than usual, but a large amount of data was gathered to ensure quality and depth of analysis.

Another limitation that must be acknowledged for generalisation purposes is that the study focused on caregivers whose older adult relative was receiving a period of convalescence prior to going home. A convalescence period has already been defined as a period of time post discharge spent in a convalescent service. In the context of this study, it relates to a dedicated bed or room in a long term residential facility where the older adult is cared for by nurses who liaise on behalf of the patient with the multidisciplinary team. The patient continues their recovery post hospitalisation usually for a week. It could be hypothesised that those caregivers who do not receive convalescence for their relative would respond differently regarding their level of readiness for the hospital discharge of an older adult. However, this was not the focus of the current study.

## **6.2 Recommendations**

This study has implications for Practice, Education and Research as outlined below.

### **6.2.1 Practice**

This study highlighted the need for early preparation of caregivers for the hospital discharge of an older adult through:

- Holistic assessment of caregivers which include: physical and psychological assessment of caregiver readiness for the hospital discharge of an older adult.
- Ensuring caregivers have family support after discharge.
- Provision of formal support for caregivers after discharge.
- Provision of oral and written information on all aspects of their relatives' care including ongoing referrals to community support services.
- Access to a name and number of a contact person within the hospital – should they have any queries or questions, worries or concerns.
- Ensuring dedicated staff to co-ordinate care and to liaise between caregivers the older adult and the multidisciplinary team.
- Provision of adequate community based supports.

### **6.2.2 Education**

Nursing staff require education on the preparation of caregivers for hospital discharge through:

- Ongoing education for nurses at post-graduate level with regards to discharge planning for caregivers of older adults.
- Development and implementation of personalised discharge plans to include caregiver, older adult patient and the multidisciplinary team.



- Strategies to support staff in attending conferences, Continuous Professional Development (CPD) modules and post graduate programs to facilitate advanced knowledge on caregiver readiness for the hospital discharge of an older adult
- Facilitating education of staff and caregivers on discharge planning to assist older adults to live at home on a long term basis

### **6.2.3 Research**

The study highlights the need for:

- Development of a tool to assess caregiver physical and psychological readiness
- Further research on caregiver readiness for the hospital discharge of an older adult who is discharged directly home without a period of convalescence.
- Assessment of caregivers on a long term basis to include a longitudinal study of caregivers at the time of discharge six weeks and 12 weeks later to monitor their physical and psychological needs, experience and progress.

### **6.2.4 Policy**

The study highlights the need to:

- Develop and improve current national and local policies to support caregivers to care for their older relative at home following discharge from hospital as highlighted by WHO and the International Society for Quality in Health Care (ISQua) (Amalberti *et al.* 2018).
- Have policies in place to enhance support for caregivers before hospital discharge, to ensure caregivers are ready to take their older adult relative home.
- Ensure continued review and enhancement of community-based supports for home based care of older adults.

### **6.2.5 Dissemination**

Findings of this qualitative study will be made accessible to participants, nurses and the general public through:

- Thus far a publication in a peer reviewed journal (Galvin *et al.* 2017).
- A follow-up paper is currently being prepared.
- A copy of this thesis will be available in the university library and will be made available online.
- Presentations for nurses at local conferences.
- Oral and poster presentations at national and international conferences.

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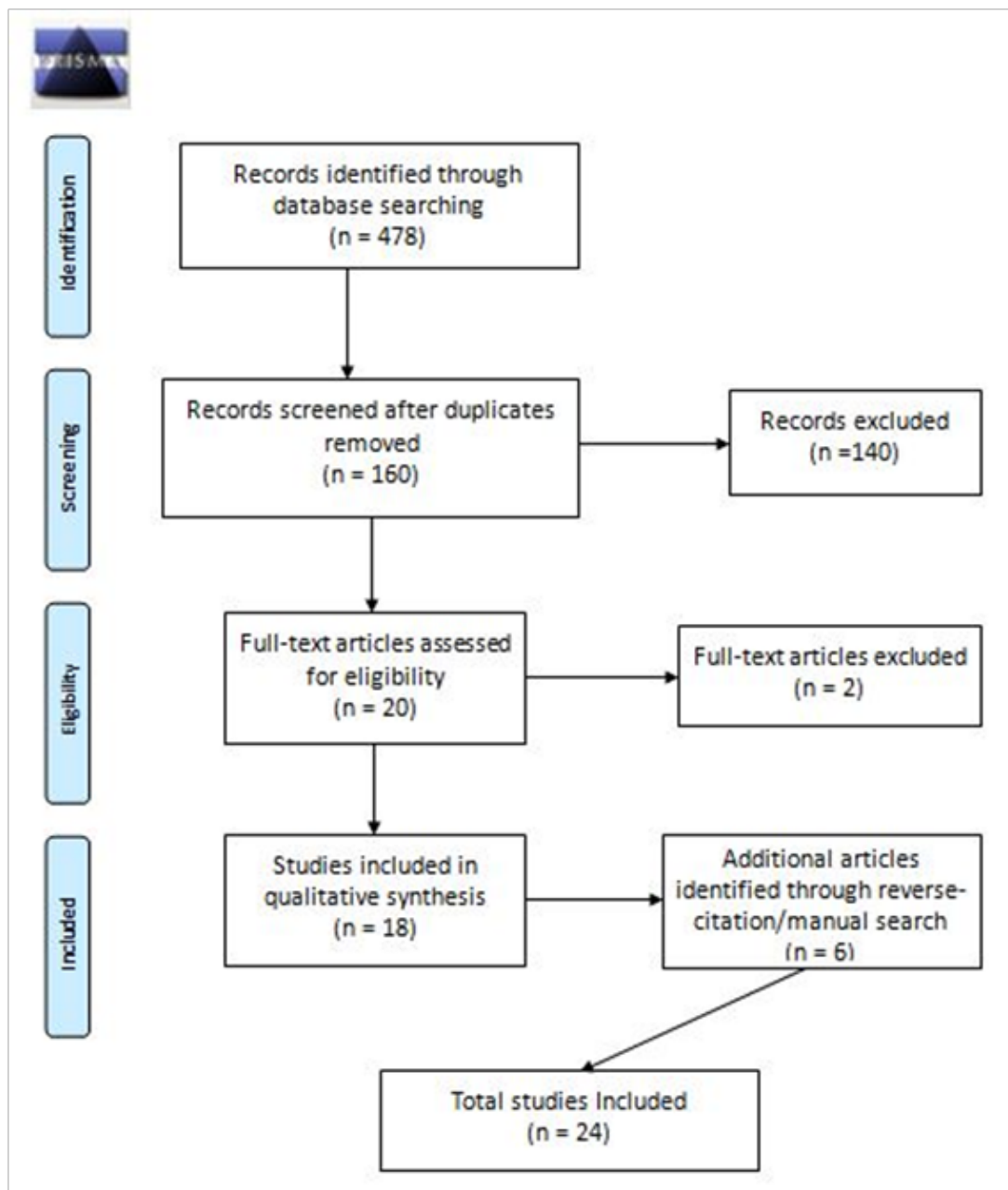
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## **Appendices**

### **Appendix 1 - Walker and Avant's 8 step process**

1. Selection of a concept;
2. Determining the aim of the analysis;
3. Identification of all possible uses of the concept;
4. Determining the defining attributes;
5. Identification of a model case of the concept;
6. Identification of borderline, related, contrary, invented and illegitimate cases;
7. Identification of antecedents and consequences;
8. Definition of empirical referents

## Appendix 2 - Concept analysis Prisma flow chart



### Appendix 3 - Table of literature characteristics for concept analysis

	Source	Country	Researcher Profession	Study Design	Data Collection	Sample
1	Anthony and Hudson-Barr (2004)	USA	Nursing	Qualitative -Descriptive longitudinal design	Semi-structured interview consisting of open-ended question	n=44 >21 years old (M= 59 years) surgical patients with planned admission
2	Balaban <i>et al.</i> (2008)	USA	Medicine	Quantitative -Intervention	Baseline characteristics and outcomes from medical health records	n= 96 (47 in the intervention group and 49 as concurrent controls)
3	Block <i>et al.</i> (2014)	USA	Medicine	Qualitative	Written reflections completed before and after a workshop	n=78 medical students
4	Bobay <i>et al.</i> (2010)	USA	Nursing	Quantitative -Comparative design	QDTS, RHDS, demographics	n=1458 QDTS n= 1449 RHDS patients >55 years
5	Brent and Coffey (2013)	Ireland	Nursing	Quantitative -Descriptive and correlational	RHDS	n=50 hip surgery patients of which majority were >75 years
6	Carroll and Dowling (2007)	Ireland	Nursing	Literature review	Review procedure and inclusive dates are not disclosed in the article.	222 relevant hits and was then limited to primary research studies
7	Clark <i>et al.</i> (1997)	Australia	Occupational Therapy	Quantitative -Comparative design	Questionnaires	n=71 patients >60 years n=52 caregivers
8	Coffey and McCarthy (2013)	Ireland	Nursing	Quantitative -Descriptive correlational design	RHDS, Demographic and Community Resource Questionnaire	n=335 patients >65 years
9	Dalton and Gottlieb (2003)	Canada	Nursing	Concept analysis	Chinn and Kramer's concept analysis technique	n=5 living with multiple sclerosis over 42 client encounters (28 face-to-face encounters; 14 telephone contacts)
10	Efraimsson <i>et al.</i> (2003)	Sweeden	Nursing	Qualitative -Case study	Discharge planning conference	n=1 The case, or study object, in this study is the discharge planning conference
11	Fiore <i>et al.</i> (2012)	Australia	Physiotherapy	Literature review	Primary research applying hospital discharge criteria following colorectal surgery from Jan 1996 to Oct 2009	156 studies identified by the search strategy described 70 different sets of criteria to indicate readiness
12	Fowler (1998)	USA	Nursing	Concept analysis	The Wilsonian method	
13	Hook (2006)	USA	Nursing	Concept analysis	Rodgers' evolutionary method	n= 62 multidisciplinary literature published between 2000 and 2004
14	Mabire <i>et al.</i> (2015)	Switzerland	Nursing	Quantitative - Crosssectional	RHDS, Discharge planning components, Post discharge service utilisation, Demographics	n=235 >75 years
15	Mabire <i>et al.</i> (2015) 3 country	Switzerland, Ireland, USA	Nursing	Quantitative	Secondary analysis of hospital studies data from three countries	n=998 medical-surgical older patients >65 years
16	Mainarich (2005)	USA	Nursing	Nursing reflection	Case	n=1 patient and n=1 caregiver
17	Makaryus and Friedman (2005)	USA	Medicine	Quantitative	Survey	n=43 patients
18	Malagon-Maldonado <i>et al.</i> (2015)	USA	Nursing, Midwifery	Quantitative	Demographic questionnaire, a quality of discharge teaching questionnaire, a readiness for discharge questionnaire, a coping and outcomes questionnaire	n=185 mothers
19	Nosbusch <i>et al.</i> (2011)	USA	Nursing	Literature review	Focused on discharge planning for patients' transition from hospital to home and the role of bedside nurse working in adult medical-surgical, intermediate care, or critical care units from 1990-2009	n=38 studies 7 themes
20	Rydemán & Törnkvist (2010)	Sweeden	Community nursing	Qualitative -Grounded theory	Semi-structured interview	n=26 older persons >65 years and their relatives
21	Weiss & Piacentine (2006)	USA	Nursing	Quantitative	RHDS	n=356 patients
22	Weiss <i>et al.</i> (2007)	USA	Nursing	Quantitative	Demographics, QDTS, CCS, RHDS, Post discharge utilisation and post discharge coping	n=147 adult medical surgical patients
23	Weiss <i>et al.</i> (2011)	USA	Nursing	Quantitative	RN hours-per-patient-day, Patient questionnaires, readmission and ED visits	n=1,892 medical-surgical patients
24	Weiss <i>et al.</i> (2014)	USA	Nursing	Quantitative	Prospective longitudinal design	n=254 adult medical-surgical patients and their discharging nurses

## Appendix 4 - Concept analysis literature findings

	Source	Attributes	Antecedents	Consequences
1	Anthony and Hudson-Barr (2004)	Psychological worries, Physical stability, nursing support, knowledge & information	knowledge, involvement, discharge plan, time,	
2	Balaban <i>et al.</i> (2008)	Psychological empowerment	preparation, process, time,	
3	Block <i>et al.</i> (2014)	medical support	communication, transition,	
4	Bobay <i>et al.</i> (2010)	family support, multidisciplinary support, physical state, psychological state, knowledge & information	education, quality of education, preparation, transition, psychological needs,	fewer readmissions,
5	Brent and Coffey (2013)	family support, post-discharge support, psychological coping, physical self-care, knowledge & information	quality education,	
6	Carroll and Dowling (2007)	Psychologically less stress, community support, GP & PHN support, family support, physical wellbeing,	communication, co-ordination, education, discharge plan, preparation, psychosocial wellbeing, time,	satisfaction, QoL, fewer readmissions,
7	Clark <i>et al.</i> (1997)	Physically coping, social support,	preparation,	
8	Coffey and McCarthy (2013)	Physical stability, emotionally able, family support, psychologically feeling ready.	knowledge, discharge plan, preparation,	
9	Dalton and Gottlieb (2003)	social support, psychologically feeling ready, physical energy	situation appraisal, self-care teaching, planning, preparation, process, awareness,	control
10	Efraimsson <i>et al.</i> (2003)	psychological power,		retainment of power,
11	Fiore <i>et al.</i> (2012)	physical stability, psychological feeling, home support	time,	
12	Fowler (1998)	psychological willingness & control, knowledge & information	reeva;uation, commitment, identification of barriers, precontemplation,	
13	Hook (2006)	psychological partnership with nurses		
14	Mabire <i>et al.</i> (2015)	physical condition, psychological emotion and coping, support at home, knowledge & information		
15	C. Mabire <i>et al.</i> (2015) 3 country	physical condition, psychological emotion and coping, support at	education, preparation, psychological needs, time,	
16	Mainarich (2005)	Family situation, physical capabilities, psychological adjustment	preparation,	
17	Makaryus and Friedman (2005)	physician support	well written instructions, time for discussion, time,	
18	Malagon-Maldonado <i>et al.</i> (2015)	Physical status, psychological coping, service support		
19	Nosbusch <i>et al.</i> (2011)	nursing support, family support,	quality communication, discharge education, planning, preparation, time,	
20	Rydeman and Törnkvist (2010)	physical ability, support of where to turn, psychological knowing how to manage.	worry about managing at home, preparation, time,	fewer readmissions,
21	Weiss and Piacentine (2006)	Physical stability, community support, emotional support, psychological, coping.	preparation, time,	
22	Weiss <i>et al.</i> (2007)	Physical stability, social support, psychological coping		
23	Weiss <i>et al.</i> (2011)	emotional support, physical support, community support, psychological feeling & coping,	preparation,	
24	Weiss <i>et al.</i> (2014)	personal staus, psychological coping, expected support		

## Appendix 5 - Readiness for hospital discharge: A concept analysis

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### CONCEPT ANALYSIS

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## Readiness for hospital discharge: A concept analysis

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#### Abstract

**Aim:** To report on an analysis on the concept of 'readiness for hospital discharge'.

**Background:** No uniform operational definition of 'readiness for hospital discharge' exists in the literature; therefore, a concept analysis is required to clarify the concept and identify an up-to-date understanding of readiness for hospital discharge. Clarity of the concept will identify all uses of the concept; provide conceptual clarity, an operational definition and direction for further research.

**Design:** Literature review and concept analysis.

**Method:** A review of literature was conducted in 2016. Databases searched were: Academic Search Complete, CINAHL Plus with Full Text, PsycARTICLES, Psychology and Behavioural Sciences Collection, PsycINFO, Social Sciences Full Text (H.W. Wilson) and SocINDEX with Full Text. No date limits were applied.

**Results:** Identification of the attributes, antecedents and consequences of readiness for hospital discharge led to an operational definition of the concept. The following attributes belonging to 'readiness for hospital discharge' were extracted from the literature: physical stability, adequate support, psychological ability, and adequate information and knowledge.

**Conclusion:** This analysis contributes to the advancement of knowledge in the area of hospital discharge, by proposing an operational definition of readiness for hospital discharge, derived from the literature. A better understanding of the phenomenon will assist healthcare professionals to recognize, measure and implement interventions where necessary, to ensure patients are ready for hospital discharge and assist in the advancement of knowledge for all professionals involved in patient discharge from hospital.

#### KEYWORDS

concept, discharge, health care, hospital, nursing, prepared, readiness, theory

### 1 | INTRODUCTION

The assessment of a patient's readiness for hospital discharge has been identified as a central component of the discharge planning process (Smith-Johnson, Davis, Burns, Montgomery, & McGee, 2015; Weiss et al., 2007). Research in the area of hospital discharge is of international relevance, as challenges in relation to hospital discharge

are a recurring global theme. Issues such as reducing the cost of health care have resulted in shorter hospital stays (Anthony & Hudson-Barr, 2004; Balaban, Weissman, Samuel, & Woolhandler, 2008; Carroll & Dowling, 2007; Coffey & McCarthy, 2013; Weiss et al., 2007). The result in many cases is that patients are not ready to go home because, there is less time for discharge preparation (Balaban et al., 2008; Weiss et al., 2007).

This paper describes a concept analysis of "readiness for hospital discharge" using the eight-step process by Walker and Avant (2011).



There is an absence of a unified definition and no concept analysis exists on this phenomenon. As the concept examined here is behavioural, concerned with understanding an experience (Cronin, Ryan, & Coughlan, 2010), the objective of this analysis was to identify which phenomena match the concept of readiness for hospital discharge and which do not.

## 2 | BACKGROUND

The concept of readiness for hospital discharge was initially defined by Fenwick (1979), as the patient's feeling of being prepared to face reality. Steele and Sterling (1992) described patient readiness as complex, providing an estimate of a person's ability to leave the hospital. Home readiness is a term used in the anaesthesia literature and describes patients at a stage of sufficient recovery to safely discharge (Korttila, 1995). A hospital discharge is deemed successful if there is increased quality of life (QoL), patient satisfaction and no readmission for the same illness within 6 weeks (Carroll & Dowling, 2007).

Rapid patient turnover results in less time to comprehensively prepare patients for hospital discharge (Anthony & Hudson-Barr, 2004). According to Weiss et al. (2007), readiness is now a central component of the discharge planning process. Readiness has been identified as an outcome indicator, where poor readiness for hospital discharge leads to readmission (Coffey & McCarthy, 2013; Weiss, Costa, Yakusheva, & Bobay, 2014; Weiss, Yakusheva, & Bobay, 2010, 2011). Nosbusch, Weiss, and Bobay (2011) conveyed that preparation for discharge should begin prior to admission and assert that the staff nurse, who has the most contact with the patient, plays a critical role in preparing for home. However, preparation for discharge is time-consuming and discharge preparation often appears rushed (Block, Morgan-Gouveia, Levine, & Cayea, 2014).

There is a multiplicity of professionals involved in the discharge process, all using multiple discharge methods and all use different criteria for the assessment of readiness for discharge. Professionals are often focused on their own areas of responsibility and formal education on safe transitions of care is not universal. Some educators focus on only one component of the discharge process, such as medication reconciliation (Block et al., 2014). Therapy professionals focus on the functional capacity of patients as being central to preparation (Clark, Steinberg, & Bischoff, 1997). Fiore et al. (2012) discovered that discharge criteria focused mainly on physical readiness and poor consistency in the terminology used to describe readiness for hospital discharge. Nurses have the most frequent contact with patients and are responsible for discharge preparation in most cases (Nosbusch et al., 2011; Weiss et al., 2011). Fowler (1998) discussed the necessity of nurses recognizing patient readiness, so that interventions are incorporated into patient care at optimum time. Carroll and Dowling (2007) asserted that the bedside staff nurse was best placed to coordinate hospital discharge, with all other healthcare professionals supporting. Weiss et al. (2011) discovered that when patients had more time with the nurse, discharge preparation was more effective.

### Why is this research needed?

- The assessment of a patient's readiness for hospital discharge has been identified as a central component of the discharge planning process.
- The literature lacks consistent terminology to describe readiness for hospital discharge and conceptual clarity is needed.
- More clarity around the concept of patient readiness for hospital discharge is necessary to result in a positive impact on patient and service outcomes.

### What are the key findings?

- The literature review identified substantial variation in terms used to describe readiness for hospital discharge.
- The attributes identified for readiness for hospital discharge were: physical stability, adequate support, psychological ability and adequate information and knowledge.
- Readiness for hospital discharge is both a state and a process characterized by physical stability and competence to manage self-care at home; adequate support to cope after leaving the hospital; psychological ability to manage the process; and adequate information and knowledge to respond to common problems.

### How should the findings be used to influence policy/practice/research/education?

- Having a uniform definition/terminology to describe readiness for hospital discharge will influence policy and practice.
- Adding discharge readiness as a variable in models for predicting readmissions should prove useful to identify patients who are at high risk of readmission.
- Clarity in relation to antecedents' attributes and consequences of readiness for hospital discharge will be of value in the education and development of healthcare professionals involved in the discharge of patients from hospital.

On the other hand, a lack of patient involvement in the discharge plan can lead to feelings of unreadiness (Anthony & Hudson-Barr, 2004). Bobay, Jerofke, Weiss, and Yakusheva (2010) affirmed that assessment and identification of postdischarge needs during hospitalization prevent problems. To improve the understanding of readiness for discharge, a unified operational definition is necessary. Therefore, the aim of this concept analysis was to develop an operational definition of the phenomenon "readiness for hospital discharge". Other aims are to identify all uses of the concept, to provide conceptual clarity and to provide direction for future research. The author used the Walker and Avant (2011) process;

their eight-step process is outlined in Table 1 and is a modified version of the Wilson (1963) process.

### 3 | DATA SOURCES

In 2016, a scoping search was carried out initially, followed by a search of the empirical literature in the following databases; Academic Search Complete, CINAHL Plus with Full Text, PsycARTICLES, Psychology and Behavioural Sciences Collection, PsycINFO, Social Sciences Full Text (H.W. Wilson) and SocINDEX with Full Text. Articles were not excluded by time limit because one of the aims of this analysis was to identify all uses of the concept.

Keywords used in the literature search were: Ready, Readiness, Prepared, Prepare, Preparedness, Preparation, Hospital, Discharge and "Concept analysis". This search generated 478 hits. Inclusion criteria were: English language and academic journals, as the number of articles were vast. Using exclusion criteria and narrowing by subject thesaurus, 160 articles (title and abstract) were examined for relevance. Finally, the reference lists of all identified papers were hand searched for other relevant cited articles. The final number of academic journal articles deemed relevant and included in the concept analysis was 24 articles. A PRISMA flow chart depicting this is available at Figure 1. The Collins (2014) English dictionary and thesaurus (Collins 2015) were used to provide definition of the concept.

Using the Walker and Avant (2011) process, papers were first read in their entirety. Then a data extraction table and a computer-assisted qualitative analysis package were used to extract and categorize the attributes, antecedents, consequences and related concepts. Initially, the relevant studies were grouped by study type; there were two literature reviews, three concept analysis of readiness and 19 empirical research papers related to readiness for hospital discharge. The papers were mainly authored by nurses; three were medical professionals and two therapy professionals. Many countries were represented; the vast majority were of USA origin with Australia, Canada, Ireland, Sweden and Switzerland also represented. The analysis generated the following results.

**TABLE 1** Walker and Avant (2011)—eight-step process

1. Selection of a concept
2. Determining the aim of the analysis
3. Identification of all possible uses of the concept
4. Determining the defining attributes
5. Identification of a model case of the concept
6. Identification of borderline, related, contrary, invented and illegitimate cases
7. Identification of antecedents and consequences
8. Definition of empirical referents

## 4 | RESULTS

### 4.1 | Uses of the concept

Collins (2014) English dictionary define readiness as: a state of completion or preparedness, make ready or get ready or prepare oneself, to put in a state of readiness or to prepare. Other definitions offered were: prepared and waiting for the guest's arrival and prepared in advance of use (Collins 2014). Hospital discharge in this analysis is defined in its own right by Collins (2014) as to release or allow to go: the hospital discharged the patient.

Collins (2015) gave the following synonyms for readiness: willingness, inclination, eagerness, preparation; and antonyms include unreadiness and unpreparedness. The author focused on the following: to get ready as in prepare oneself, the state of being ready and prepared in advance, in the context of leaving hospital or hospital discharge.

In the literature, readiness has been analysed in relation to change. Fleury (1991) determined that individual readiness to change consisted of re-evaluation of lifestyle, identification of barriers and commitment. Fowler (1998) examined nursing interventions that assisted patients to incorporate change and discovered that interventions must be presented to patients at a time when the patient's ability to succeed is optimal. They established that the ability to recognize readiness in patients is essential.

Efraimsson, Rasmussen, Gilje, and Sandman (2003) asserted that effective communication was central to readiness for discharge but preparation focused mainly on the patient's medical state. Anthony and Hudson-Barr (2004) asked patients their needs for discharge. Patients rated information about resources, knowledge of their home-going needs, active involvement in the process and medications as most important for readiness to go home.

Carroll and Dowling (2007) suggested that open and honest communication between the multidisciplinary team is required to prepare the patient for hospital discharge. According to these researchers, unreadiness for discharge was caused by poor history taking, poor nursing handover, differing opinions on who coordinates the discharge and the quality of communication when educating patients (Carroll & Dowling, 2007). Readiness for hospital discharge is usually judged by clinical criteria, but Weiss et al. (2007) examined predictors of discharge readiness and found that quality of discharge teaching was the strongest predictor of discharge readiness. Importantly, the perception of readiness may be different between patient and provider (Weiss et al., 2007).

Bobay et al. (2010) described patient readiness for hospital discharge as multidimensional. The dimensions include assessment of physical, social and psychological states; understanding their illness, medications, physical limitations and what to expect; and community resources and support. They also noted that when patient needs were accurately assessed early in their hospital stay, patient readiness for hospital discharge was more successful (Bobay et al., 2010).

According to Rydeman and Törnkvist (2010), professional skills when preparing the patient for home increased, the level of



The first and most acknowledged attribute is physical stability. Stable vital signs, adequate intake and output, normal elimination, adequate ambulation, minimal bleeding, pain control, absence of nausea or vomiting, functional ability and competence to manage self-care at home were the most cited physical signs of readiness for discharge (Anthony & Hudson-Barr, 2004; Bobay et al., 2010; Weiss & Piacentine, 2006; Weiss et al., 2007).

The attribute of psychological ability is the influence of preparation on the mental make-up of the individual, causing the desired feeling of readiness for hospital discharge (Collins 2014). Felt readiness is the patient's reality and their conception of life at home influences their psychological level of readiness (Coffey & McCarthy, 2013). Psychological ability requires the patient to cope and retain control (Bobay et al., 2010; Carroll & Dowling, 2007; Efraimsson et al., 2003). Awareness of ability and a need to be self-reliant are part of self-perceived readiness (Balaban et al., 2008; Coffey & McCarthy, 2013; Dalton & Gottlieb, 2003; Efraimsson et al., 2003; Fowler, 1998; Weiss & Piacentine, 2006; Weiss et al., 2007, 2011).

Collins (2014) described support as giving aid or courage, therefore, the attribute of adequate support is both physical and psychological. Knowing what support was available assisted patients in feeling ready (Fiore et al., 2012; Mabire, Coffey, & Weiss, 2015; Rydeman & Törnkvist, 2010; Weiss & Piacentine, 2006; Weiss et al., 2011). Support comes from many sources including friends and family, nurses and other members of multidisciplinary teams and voluntary services. An adequate support system is a positive force in feeling ready (Brent & Coffey, 2013; Dalton & Gottlieb, 2003; Efraimsson et al., 2003; Weiss et al., 2007), postdischarge supports including GP and public health nurse help cope with multiple demands after leaving the hospital (Bobay et al., 2010).

According to Artinian (1993), information influences readiness. Knowledge includes the perceived adequacy of information needed to respond to common concerns and problems during the posthospitalization period (Mabire, Coffey, & Weiss, 2015). The possession of knowledge in relation to: caring for oneself, personal needs; medical needs; problems that might occur; who and when to call; what happens next and available services, is a component of feeling ready for hospital discharge. (Anthony & Hudson-Barr, 2004; Brent & Coffey, 2013; Fowler, 1998; Mabire, Coffey, & Weiss, 2015). Information was highly associated with how physically ready the person felt, how much they felt they could cope and how much support they expected to have at home (Bobay et al., 2010).

#### 4.3 | Antecedents

Antecedents are those events or incidents that must be in place for the concept to occur and cannot be a defining attribute for that concept (Walker & Avant, 2011). According to Dalton and Gottlieb (2003), prior to readiness for hospital discharge, a patient undergoes a self-appraisal, where they decide whether to change from unreadiness to readiness. The patient appraises their situation and weighs the benefit of preparing for readiness, at this stage the patient commits to preparation and identifies the barriers (Dalton & Gottlieb, 2003).

When the patient has gained sufficient levels of energy, they begin to prepare, they show desire for involvement and become aware of the benefits of preparation (Anthony & Hudson-Barr, 2004; Balaban et al., 2008; Bobay et al., 2010; Carroll & Dowling, 2007; Clark et al., 1997; Coffey & McCarthy, 2013; Mabire, Coffey, & Weiss, 2015; Mainarich & Silverstein, 2005; Nosbusch et al., 2011; Rydeman & Törnkvist, 2010; Weiss & Piacentine, 2006; Weiss et al., 2011). The preparation must be patient led (Anthony & Hudson-Barr, 2004), at their pace and level of understanding, because too much too soon can destabilize and prevent readiness (Dalton & Gottlieb, 2003).

At this stage, contemplation occurs and then action, which involves cognitive and emotional factors as well as commitment (Dalton & Gottlieb, 2003). Verbal and written instructions and quality education help the process at this optimum time (Bobay et al., 2010; Brent & Coffey, 2013; Coffey & McCarthy, 2013; Dalton & Gottlieb, 2003; Mabire, Coffey, & Weiss, 2015; Makaryus & Friedman, 2005; Nosbusch et al., 2011). Multiple short episodes of communication can be of more value in preparing or making the patient ready to go home and skilled delivery is paramount (Bobay et al., 2010). Coordination of after discharge support is helpful in making the patient ready and builds confidence. This includes detailed clear reports to health and social care professionals, medication reconciliation and communication with a main carer (Carroll & Dowling, 2007; Coffey & McCarthy, 2013; Nosbusch et al., 2011). The antecedents extracted from the literature are listed in Table 2, along with the attributes and consequences.

Caring issues, activities of daily living and where to turn were areas of concern by patients in preparation for discharge (Rydeman & Törnkvist, 2010). Good physical and emotional condition as "felt" by the patient and enough time given by health providers to achieve this is a must (Anthony & Hudson-Barr, 2004; Coffey & McCarthy, 2013; Fiore et al., 2012; Makaryus & Friedman, 2005; Nosbusch et al., 2011; Weiss & Piacentine, 2006). Ensuring that patients have the skills required to cope at home, ability to adjust to the situation and the confidence to cope with demands takes time (Anthony & Hudson-Barr, 2004; Mabire, Coffey, & Weiss, 2015; Nosbusch et al., 2011).

Knowing that they have emotional and instrumental assistance at home helps with any unexpected obstacles and where to turn for support as such if difficulties arise. The importance of feeling safe, confident and supported were emphasized (Bobay et al., 2010; Coffey & McCarthy, 2013; Dalton & Gottlieb, 2003; Fiore et al., 2012; Rydeman & Törnkvist, 2010; Weiss & Piacentine, 2006). Rushing the discharge process can leave feelings of unpreparedness leading to unreadiness. Therefore, the earlier the preparation is commenced, the better the outcome (Mabire, Lecerf, et al., 2015; Nosbusch et al., 2011).

#### 4.4 | Consequences

Consequences are outcomes that occur as a result of the concept and they can shed light on the social context where the concept is

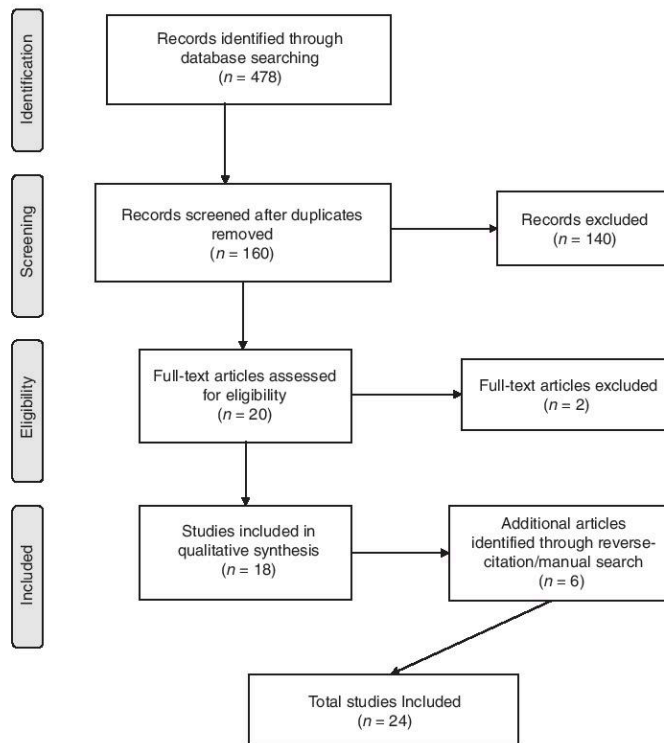


FIGURE 1 PRISMA flow diagram

discharge readiness and feeling prepared meant having a satisfactory conception of how life at home would be. Caring issues, activities of daily living and where to turn for support were deemed most important in feeling prepared. Fiore et al. (2012) discovered 70 different sets of criteria to indicate readiness for discharge and those most frequently cited were tolerance of oral intake, return of bowel function, adequate pain control and adequate mobility.

Weiss et al. (2011) established that adequate staffing reduced readmissions through quality discharge teaching. When Brent and Coffey (2013) examined hip fracture patients' perception of readiness for discharge, higher quality discharge teaching was associated with higher levels of readiness for discharge and readiness levels decreased as age increased. In addition, Brent and Coffey (2013) found that when patients were asked if they were ready for discharge, most answered yes, but on further investigation using the readiness for hospital discharge scale (RHDS) developed by Weiss and Piacentini (2006), results showed a much lower degree of readiness, indicating that a more in-depth assessment of patient readiness is a necessary part of the discharge process.

Weiss et al. (2011) suggested that felt readiness reflected the patient's reality and Coffey and McCarthy (2013) found that a lack of home support was a barrier to discharge readiness. At discharge,

differences in readiness existed as age increased and a lower perception of readiness at discharge increased the use of supports postdischarge (Coffey & McCarthy, 2013). Weiss et al. (2014) also established that nurse assessment of low discharge readiness was associated with an increase in readmission. While in obstetrics, Malagon-Maldonado, Hiner, and Lanciers (2015) found that maternal/infant length of stay, delivery mode and the quality of discharge teaching were predictive of readiness for hospital discharge. This exploration of multiple uses of readiness and readiness for hospital discharge allowed identification of multiple and related uses of the concept, which are helpful in defining the attributes (Walker & Avant, 2011).

## 4.2 | Attributes

Walker and Avant (2011) defined the term "attributes" as those characteristics that must always be present if the concept exists and concepts are generally expressed in statements that indicate what are considered to be the attributes. Collins (2014) defines an attribute as a verb, "belonging to" or "linked to". The following attributes belonging to readiness for hospital discharge were extracted from the literature: physical stability, adequate support, psychological ability, and adequate information and knowledge.

TABLE 2 Literature characteristics

	Source	Attributes	Antecedents	Consequences
1	Anthony and Hudson-Barr (2004)	Psychological worries, Physical stability, nursing support, knowledge and information	Knowledge, involvement, discharge plan, time	
2	Balaban et al. (2008)	Psychological empowerment	Preparation, process, time	
3	Block et al. (2014)	Medical support	Communication, transition	
4	Bobay et al. (2010)	Family support, multidisciplinary support, physical state, psychological state, knowledge and information	Education, quality of education, preparation, transition, psychological needs	Fewer readmissions
5	Brent and Coffey (2013)	Family support, postdischarge support, psychological coping, physical self-care, knowledge and information	Quality education	
6	Carroll and Dowling (2007)	Psychologically less stress, community support, GP & PHN support, family support, physical well-being	Communication, co-ordination, education, discharge plan, preparation, psychosocial well-being, time	Satisfaction, QoL, fewer readmissions
7	Clark et al. (1997)	Physically coping, social support	Preparation	
8	Coffey and McCarthy (2013)	Physical stability, emotionally able, family support, psychologically feeling ready	Knowledge, discharge plan, preparation	
9	Dalton and Gottlieb (2003)	Social support, psychologically feeling ready, physical energy	Situation appraisal, self-care teaching, planning, preparation, process, awareness	Control
10	Efrainsson et al. (2003)	Psychological power		Retainment of power
11	Fiore et al. (2012)	Physical stability, psychological feeling, home support	Time	
12	Fowler (1998)	Psychological willingness & control, knowledge & information	Re-evaluation, commitment, identification of barriers, pre-contemplation	
13	Hook (2006)	Psychological partnership with nurses		
14	Mabire, Coffey, & Weiss (2015), Mabire, Lecerf, et al. (2015)	Physical condition, psychological emotion and coping, support at home, knowledge & information		
15	Mabire, Coffey, & Weiss (2015), Mabire, Lecerf, et al., (2015), three country	Physical condition, psychological emotion and coping, support at home	Education, preparation, psychological needs, time	
16	Mainarch and Silverstein (2005)	Family situation, physical capabilities, psychological adjustment	Preparation	
17	Makaryus and Friedman (2005)	Physician support	Well written instructions, time for discussion, time	
18	Malagon-Maldonado et al. (2015)	Physical status, psychological coping, service support		
19	Nosbusch et al. (2011)	Nursing support, family support	Quality communication, discharge education, planning, preparation, time	

(Continues)



TABLE 2 (Continued)

Source	Attributes	Antecedents	Consequences
20 Rydeman and Törnkvist (2010)	Physical ability, support of where to turn, psychological knowing how to manage	Worry about managing at home, preparation, time	Fewer readmissions
21 Weiss and Piacentini (2006)	Physical stability, community support, emotional support, psychological, coping	Preparation, time	
22 Weiss et al. (2007)	Physical stability, social support, psychological coping		
23 Weiss et al. (2011)	Emotional support, physical support, community support, psychological feeling & coping	Preparation	
24 Weiss et al. (2014)	Personal status, psychological coping, expected support		

used (Cronin et al., 2010; Walker & Avant, 2011). There are patient and provider consequences of readiness for hospital discharge.

A sense of control is a positive patient consequence of readiness for hospital discharge (Dalton & Gottlieb, 2003). Individual autonomy and power is maintained (Efraimsson et al., 2003), satisfaction is gained and there is improved QoL (Carroll & Dowling, 2007). Nurse-delivered discharge teaching increases self-care adherence and improves clinical outcomes (Bobay et al., 2010).

According to Efraimsson et al. (2003), safety and security are retained when the patient has adequate family support. In studies of discharge transitions where older people and their caregivers were encouraged to identify postdischarge needs, carers felt more prepared to manage care and received more information about care management (Bobay et al., 2010). Positive provider consequences of readiness for hospital discharge are reductions in cost of care and fewer readmissions (Bobay et al., 2010).

The literature shows how important readiness for hospital discharge is to the patient in retaining control, autonomy and dignity, as well as feeling safe, secure and supported. None of which can be maintained without the healthcare provider ensuring that the patient is ready to go home.

## 5 | CASES

### 5.1 | Model case

A model case shares all of the key characteristics of the concept, all the defining attributes and at least one of the antecedents and consequences. Ultimately, there should be no overlap or contradictions between the defining attributes and the model case (Walker & Avant, 2011).

Mrs White, a 65-year-old woman, who is a planned admission, was scheduled for a total knee replacement surgery. She has a son and a daughter, and her husband is deceased.

During her preadmission assessment, her children are present. A full medical history is taken. Her physical ability is assessed. She meets with the multidisciplinary team, who explain the procedure. On admission, she is met with the unit staff nurse who orientates her to her surroundings. The nurse initiates communication about her living circumstances and how she is going to manage at home. The nurse also explains that she will not be able to drive until the consultant says she is fit to do so. Mrs White offered to speak about this with her adult children. They discuss taking turns to stay overnight with her, calling before and after work, as well as at lunch time. They may also explore bringing her bed downstairs until she is comfortable with managing stairs on her own. They will arrange to take her to her follow-up appointments.

Mrs White speaks to the unit nurse before her operation that afternoon, the nurse records the arrangements she has made with family for support following discharge and arranges to discuss appointments and medications with Mrs White's children. The nurse will also reiterate all discharge instructions verbally and in writing to Mrs White in a couple of days when she is feeling up to discussion.

Mrs White has returned to physical stability following her surgery and she expresses that she feels well. Mrs White discusses her care thoroughly with the unit nurse and feels fully informed and knowledgeable about her treatment and care, attends her physiotherapy and is discharged on schedule. She returns to her consultant at 6 weeks and is discharged from his care with no adverse events.

This is a model case because it shows the attributes clearly. Physical stability is met; psychological ability is assessed by the nurse when communication was initiated; support of the nurse, medical and therapy team as well as family is evident; and knowledge of all care is given verbally and in print. The antecedent is the initiation of communication pre- and during admission with a consequence of a safe discharge for the patient and family with no adverse events.

## 5.2 | Related case

Mr Joe was travelling in his wheelchair in a wheelchair taxi. There was a small collision at a roundabout and his car was involved. He was brought by ambulance to the local accident and emergency, where he was examined and deemed to have no injuries and was ready for hospital discharge.

This related case illustrates the concept, but it differs because Mr Joe was admitted briefly to hospital, he did not undergo any treatment, therefore his state of readiness for hospital discharge was not altered by any change in his physical condition. This case assists in understanding the concept, in relation to what comes before the phenomenon (Walker & Avant, 2011).

## 5.3 | Limited case

Mr Black is an 84-year-old man admitted to a large medical ward of an acute hospital at 7 pm with a respiratory tract infection. He came to the ward from a busy accident and emergency unit with a brief transfer note stating that he was commenced on IV antibiotics, steroids and nebulizers. The day nursing staff handed over his care to the night staff at 8 pm having only seen him briefly to administer his IV antibiotics. There was a different unit team the following day and after the ward round, they were informed that Mr Black was to commence oral medications and is discharged home with a neighbour. Mr Black has not received information about the management of his medications. He has two inhalers in a box that he has never used before and he is on a reducing dose of another medication. Mr Black has received no information in relation to his follow-up care. Mr Black is breathless which is not normal for him, he lives alone in a two story house where the bathroom and bedroom are upstairs. He is found by his neighbour 2 days later in a state of delirium.

The limited case contains one or more but not all the attributes of the concept (Walker & Avant, 2011). The case outlined above shows poor physical stability, no adherence to psychological ability and a limited support system in place demonstrating poor readiness for hospital discharge. The patient also got limited information leading to poor knowledge of his situation.

## 6 | DEFINITIONS OF EMPIRICAL REFERENTS

Empirical referents are the means by which the defining attributes or characteristics are measurable (Walker & Avant, 2011). They may also point to instruments that are already developed and validated. Confirming that a patient is ready to go home is a difficult task, as readiness is a feeling and feelings are subjective (Mollon, 2014). Due to the abstractness of feelings, they are more difficult to measure. Probably the best way to find out if a patient is ready for hospital discharge is to ask them, but they may be unable or unwilling to share their true feelings (Mollon, 2014).

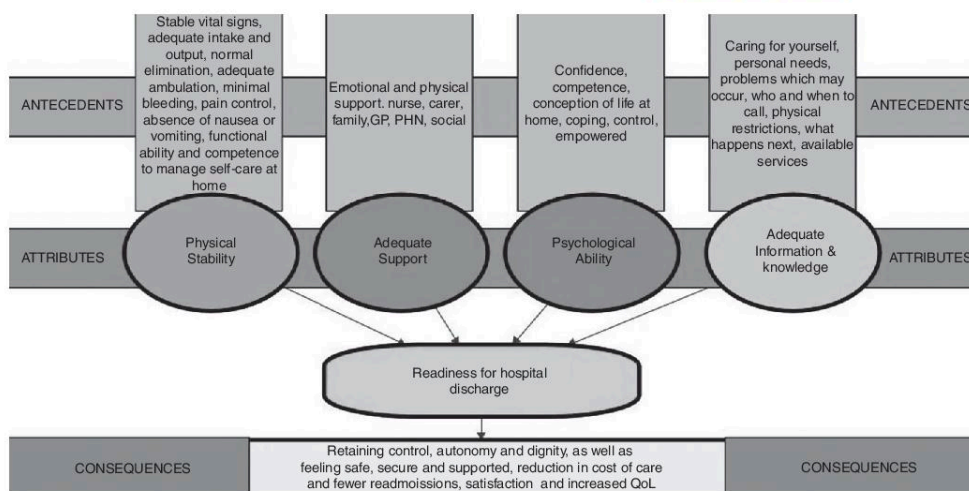
Few measures have been developed to examine readiness in the context of discharge from hospital. The Readiness for Hospital Discharge Scale (RHDS) developed in the US by Weiss and Piacentine (2006) is the only instrument that measures an individual's self-perception of readiness before leaving the hospital (Mabire, Coffey, & Weiss, 2015). This scale was specifically developed to measure self-perception of readiness to return home in hospitalized adults and results of the RHDS scale showed a lower degree of readiness compared with what the patient themselves reported when asked if they were ready (Weiss & Piacentine 2006). This instrument could assist research on other areas of readiness for hospital discharge.

## 7 | PROPOSED OPERATIONAL DEFINITION

Readiness for hospital discharge is both a state and a process. It is characterized by physical stability including functional ability and competence to manage self-care at home; has adequate support to cope with multiple demands after leaving the hospital; has psychological ability, where the patient has become confident enough to manage the transition or process; and has adequate information and knowledge to respond to common problems during the posthospitalization period. A diagram depicting the conceptual framework of readiness for hospital discharge is available at Figure 2.

## 8 | DISCUSSION

The concept "readiness for hospital discharge" was broken into simpler components to determine its internal structure and because this concept is expressed in words, the analysis was therefore an analysis of the words (Walker & Avant, 2011). Examining the uses of a concept is an important process in the cycle of concept development that allows the attributes of that concept to be identified (Walker & Avant, 2011). Another important part of concept analysis is the use of cases which exemplify how the concept is naturally and commonly used (Risjord, 2009). This analysis of the concept from different perspectives was influenced by a health sciences perspective and the proposed definition is for use in this particular area by a wide multidisciplinary team in practice and research. This concept



**FIGURE 2** Conceptual framework of readiness for hospital discharge

analysis is a contribution towards the development of a middle-range theory of clinical reasoning in nursing. Readiness assessments that identify patients at risk of low readiness for hospital discharge will assist nurses and other healthcare professionals to implement interventions, to increase patient readiness and prevent problematic discharges (Weiss et al., 2014).

Discharge teaching is vital to readiness for hospital discharge and requires a vast amount of communication. The content and mode of delivery influence the quality of information or education given to the patient, importantly less is more indicating quality over quantity (Weiss et al., 2007). Balaban et al. (2008) recommended a formal communication plan to ensure that everyone is informed of all the details involved in discharge, including written information or instructions for the patient. Nosbusch et al. (2011) recommended the improvement in continuity of information and patient education, a common path and language between disciplines, so that everyone knows what is done and what needs to be done.

This concept analysis advances nursing knowledge and the proposed definition can be used in nursing research where readiness for hospital discharge is intended as an outcome measure. It will encourage a unified use of the concept and guide the elaboration of measuring tools. The identification of antecedents' attributes and consequences of readiness for hospital discharge also distinguish this from other concepts. From its definition, readiness for hospital discharge can be developed as an explanatory middle-range theory, which conceptually captures readiness as felt by the patient to go home from hospital. Discharge readiness as experienced by the patient is not equivalent to readiness experienced by the nurse or family members (Anthony & Hudson-Barr, 2004; Weiss & Piacentine, 2006; Weiss et al., 2007), developing an understanding of patient's perception of readiness, will develop clinical practice (Weiss et al., 2007).

## 8.1 | Limitations

The purpose of this concept analysis was to define the concept of readiness for hospital discharge through a retrieval of literature from key health and social science disciplines. However there were limitations. The inclusion of additional disciplines and languages other than English may have broadened the concept. The present analysis was used to investigate a concept that is dynamic and still evolving in the practice of nursing. The antecedents, attributes and consequences could change over time as patients become more educated and prepared to manage their own health issues and as providers improve their services. The use of other methods of concept analysis, such as Rodgers' evolutionary method (Rodgers & Knaf, 1993), may have produced different results.

## 9 | CONCLUSION

Readiness for hospital discharge has been identified as a central component of discharge planning and an issue of international relevance in health care. In this paper, the first concept analysis focused on readiness for hospital discharge is introduced. The objective of this analysis was to provide conceptual clarity and direction for future research and to advance knowledge for professionals by providing an operational definition of readiness for hospital discharge. A better understanding of the phenomenon will assist health professionals to recognize measure and implement interventions where necessary, to ensure patients are ready for discharge from hospital.

By defining the attributes, antecedents and consequences of readiness for discharge through conducting a concept analysis, conceptual clarity is obtained. This clarity is an important aspect of



advancing the science related to the concept of readiness for hospital discharge and provides direction for future research on this topic. The conceptual and operational clarity provided by this analysis will inform future decision-making and interventions by healthcare providers in the area of hospital discharge. The concept of readiness for hospital discharge can be used to underpin future research, into hospital discharge in different populations and in different cultural contexts.

# CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

# AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (<http://www.icmje.org/recommendations/>)]:

- substantial contributions to conception and design, acquisition of data or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

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## Appendix 6 - Search strategy for readiness for hospital discharge

Search Strategy Readiness for Hospital Discharge						
PICO	Population	Intervention	Setting			Outcome
Databases - CINAHL Plus with Full Text, MEDLINE, PsycINFO, SocINDEX with Full Text and Cochrane	Full term to palliative	S1	S2	S3	S4	S5
Search terms	n/a	ready OR readiness OR prepar*	discharge OR "hospital discharge"	(MH "Patient Discharge")	S2 OR S3	S1 AND S4
Field	TX All Text	TX All Text	TX All Text			
Hits	n/a	1,508,945	228,237	33,404	228,237	13,135
Hits 2006-March 2019 Narrowed by: English language, Academic journals, Peer reviewed						3,607
Academic journals,						3,405
After Applying Limiters,						1,273
Read in entirety						95
Relevant						36

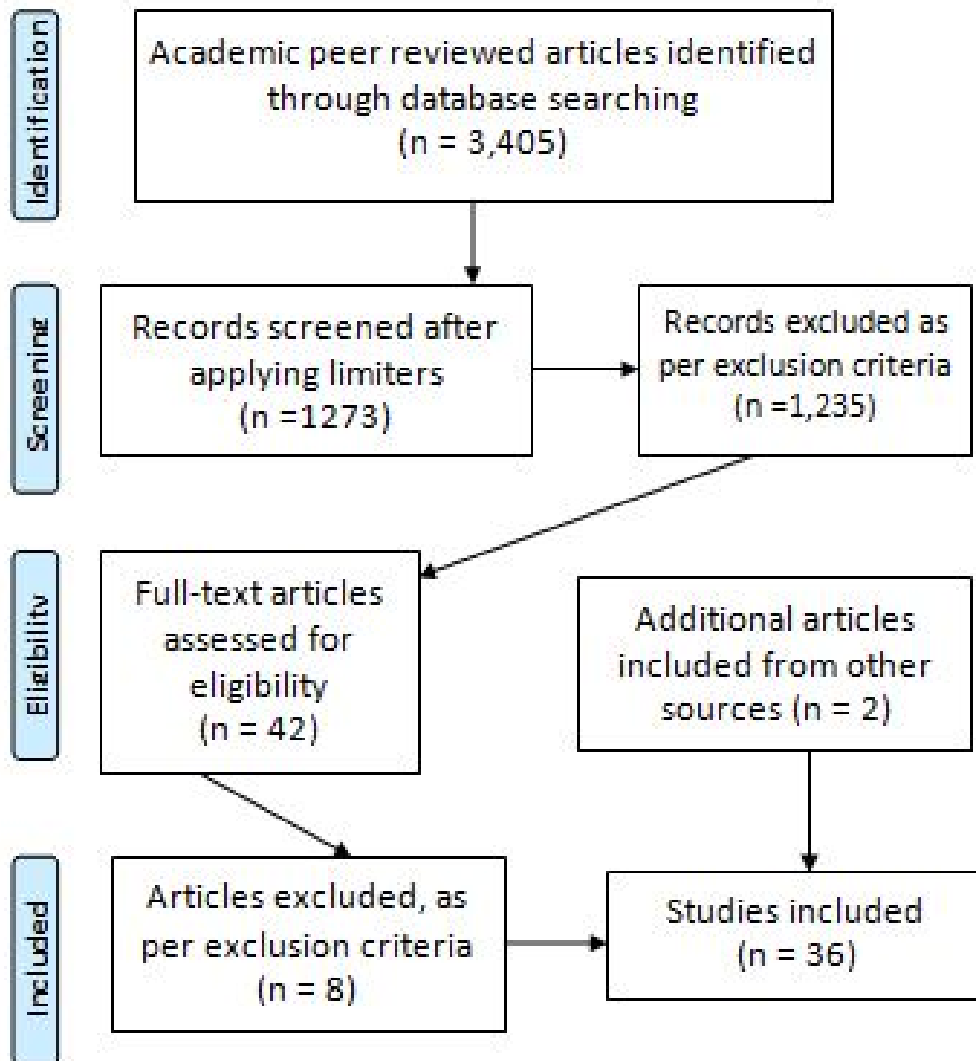
## Appendix 7 - Inclusion & exclusion criteria

Inclusion Criteria	Subject Major	Exclusion Criteria
01 Jan 2006 - 31 Dec 2016	Patient centred care	Premature
Peer Reviewed	Nursing practice	Transplant
Language: - English	Multidisciplinary care team	Dialysis
	Life experiences	Pandemics or disasters
	Instrument validation	Suicide
	Stroke patients	End of life
	Quality improvement	Schizophrenia
	Gerontologic care	Ventilated patients
	Nursing role	Spinal cord injury
	Rehabilitation	Substance abuse
	Quality of health care	Reports
	Aged	Day surgery
	Hospitalized	Commentaries
	Patient education	Prison
	Family	HIV
	Quality of life	Post anaesthesia care unit
	Hospital discharge	Veterans
	Patient attitudes	
	Continuity of patient care	
	After care	
	Stroke	
	Patient discharge education	
	Caregivers	
	Transfer, discharge	
	Discharge planning	
	Patient discharge	

## Appendix 8 - PRISMA Flow chart readiness for hospital discharge



### PRISMA Flow Diagram – Literature Review



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med* 6(7):e1000097. doi:10.1371/journal.pmed.1000097

For more information, visit [www.prisma-statement.org](http://www.prisma-statement.org).

## Appendix 9- Quality appraisal overview

Mixed Methods Appraisal Tool							
Count	RefID	First author	Year	Citation	Type of study: 1= Qual 2=RCT 3= Quant 4 Mixed Metod	S1. Are there clear research questions?	S2. Do the collected data allow to address the research questions?
1	PP 15	Mitchell	2018	Mitchell, S. E.,	1	Yes	Yes
2	PP 14	Allen	2018	Allen, J.,	1	Yes	Yes
3	PP 11	Mabire	2019	Mabire, C., Bachnick	3	Yes	Yes
4	PP 10	Kaya	2018	Kaya, Sıdika, Seda A	3	Yes	Yes
5	PP 9	Lau	2016	Lau, D., Padwal, R. S	3	Yes	Yes
6	PP 8	Schmocker	2015	Schmocker, R. K., He	3	Yes	Yes
7	PP 13	Satink	2015	Satink, T., Cup, E. H.	1	Yes	Yes
8	PP 12	Neiterman	2015	Neiterman, E., Wod	1	Yes	Yes
9	PP 7	Weiss	2014	Weiss, Costa, L. L., Y	3	Yes	Yes
10	PP 6	Brent	2013	Brent, L. & Coffey, A	3	Yes	Yes
11	PP 5	Coffey	2013	Coffey, A. & McCart	3	Yes	Yes
12	PP 4	Weiss	2011	Weiss, M. E., Yakush	3	Yes	Yes
13	PP 3	Bobay	2010	Bobay, K. L., Jerofke	3	Yes	Yes
14	PP 2	Weiss	2007	Weiss, Piacentine,	3	Yes	Yes
15	PP 1	Weiss	2006	Weiss, M. E. & Piac	3	Yes	Yes
16	HCP 10	Weiss	2019	Weiss, M. E., Yakush	2	Yes	Yes
17	HCP 9	Knier	2015	Knier, S., Stichler, J.	3	Yes	Yes
18	HCP 8	Saleh	2012	Saleh, S. S., Freire, C	2	Yes	Yes
19	HCP 5	Hesselink	2012	Hesselink, G., Flink,	1	Yes	Yes
20	HCP 4	Oliveira	2011	Oliveira, M. F., Cam	3	Yes	Yes
21	HCP 3	Connolly	2010	Connolly, M., Deato	4	Yes	Yes
22	HCP 7	Shyu	2010	Shyu, Y. I., Chen, M.	2	Yes	Yes
23	HCP 6	Shyu	2008	Shyu, Y.-I. L., Chen,	2	Yes	Yes
24	HCP 2	Dunnion	2008	Dunnion, M. E. & Ke	3	Yes	Yes
25	HCP 1	Foust	2007	Foust, J. B. (2007) Di	1	Yes	Yes
26	CG 11	Schwartz	2019	Schwartz, A. J., Ried	1	Yes	Yes
27	CG 10	Rustad	2017	Rustad, E. C., Seiger	1	Yes	Yes
28	CG 9	Toye	2016	Toye, C., Parsons, R	2	Yes	Yes
29	CG 8	Coleman	2015	Coleman, E. A. &	1	Yes	Yes
30	CG 7	Agard	2015	Ågård, A. S., Egerod	1	Yes	Yes
31	CG 6	Young	2014	Young, M. E., Lutz, B	1	Yes	Yes
32	CG 5	Gustafsson	2013	Gustafsson, L. & Bo	1	Yes	Yes
33	CG 4	Perry	2011	Perry, L. & Middleto	4	Yes	Yes
34	CG 3	Fitzgerald	2011	Fitzgerald, L. R.,	1	Yes	Yes
35	CG 2	Rydeman	2010	Rydeman, I., & Törn	1	Yes	Yes
36	CG 1	Boughton	2009	Boughton, M. & Hal	1	Yes	Yes

## Appendix 10 - Quality appraisal of qualitative studies & RCT

1. QUALITATIVE STUDIES								
Count	RefID	First author	Year	1.1. Is the qualitative approach appropriate to answer the research question?	1.2. Are the qualitative data collection methods adequate to address the research question?	1.3. Are the findings adequately derived from the data?	1.4. Is the interpretation of results sufficiently substantiated by data?	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?
1	CG 11	Schwartz	2019	Yes	Yes	Yes	Yes	Yes
2	PP 15	Mitchell	2018	Yes	Yes	Yes	Yes	Yes
3	PP 14	Allen	2018	Yes	Yes	Yes	Yes	Yes
4	CG 10	Rustad	2017	Yes	Yes	Yes	Yes	Yes
5	CG 8	Coleman	2015	Yes	Yes	Yes	Yes	Yes
6	CG 7	Agard	2015	Yes	Yes	Yes	Yes	Yes
7	PP 13	Satink	2015	Yes	Yes	Yes	Yes	Yes
8	PP 12	Neiterman	2015	Yes	Yes	Yes	Yes	Yes
9	CG 6	Young	2014	Yes	Yes	Yes	Yes	Yes
10	CG 5	Gustafsson	2013	Yes	Yes	Yes	Yes	Yes
11	HCP 5	Hesselink	2012	Yes	Yes	Yes	Yes	Yes
12	CG 3	Fitzgerald	2011	Yes	Yes	Yes	Yes	Yes
13	CG 2	Rydeman	2010	Yes	Yes	Yes	Yes	Yes
14	CG 1	Boughton	2009	Yes	Yes	Yes	Yes	Yes
15	HCP 1	Foust	2007	Yes	Yes	Yes	Yes	Yes

2. RANDOMIZED CONTROLLED TRIALS								
Count	RefID	First author	Year	2.1. Is randomization appropriately performed?	2.2. Are the groups comparable at baseline?	2.3. Are there complete outcome data?	2.4. Are outcome assessors blinded to the intervention provided?	2.5 Did the participants adhere to the assigned intervention?
1	HCP 10	Weiss	2019	Yes	Yes	Yes	Can't tell	Yes
2	CG 9	Toye	2016	Yes	Yes	Yes	moderately successful	Yes
3	HCP 8	Saleh	2012	Yes	Yes	Yes	Can't tell	Yes
4	HCP 7	Shyu	2010	Yes	Yes	Yes	Can't tell	Yes
5	HCP 6	Shyu	2008	Yes	Yes	Yes	Can't tell	Yes

## Appendix 11 - Quality appraisal quantitative descriptive & mixed methods

3. QUANTITATIVE DESCRIPTIVE STUDIES								
Count	RefID	First author	Year	4.1. Is the sampling strategy relevant to address the research question?	4.2. Is the sample representative of the target population?	4.3. Are the measurements appropriate?	4.4. Is the risk of nonresponse bias low?	4.5. Is the statistical analysis appropriate to answer the research question?
1	PP 11	Mabire	2019	Yes	Yes	Yes	Yes	Yes
2	PP 10	Kaya	2018	Yes	Yes	Yes	Yes	Yes
3	PP 9	Lau	2016	Yes	Yes	Yes	Yes	Yes
4	PP 8	Schmocker	2015	Yes	Yes	Yes	Can't tell	Yes
5	HCP 9	Knier	2015	Yes	Yes	Yes	Can't tell	Yes
6	PP 7	Weiss	2014	Yes	Yes	Yes	Can't tell	Yes
7	PP 6	Brent	2013	Yes	Yes	Yes	Yes	Yes
8	PP 5	Coffey	2013	Yes	Yes	Yes	Can't tell	Yes
9	PP 4	Weiss	2011	Yes	Yes	Yes	Can't tell	Yes
10	HCP 4	Oliveira	2011	Yes	Yes	Yes	Yes	Yes
11	PP 3	Bobay	2010	Yes	Yes	Yes	Can't tell	Yes
12	HCP 2	Dunnion	2008	Yes	Yes	Yes	Can't tell	Yes
13	PP 2	Weiss	2007	Yes	Yes	Yes	Can't tell	Yes
14	PP 1	Weiss	2006	Yes	Yes	Yes	Can't tell	Yes

4. MIXED METHODS STUDIES								
Count	RefID	First author	Year	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?	5.2. Are the different components of the study effectively integrated to answer the research question?	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?
1	CG 4	Perry	2011	Yes	Yes	Yes	Yes	Yes
2	HCP 5	Connolly	2010	Yes	Yes	Yes	Yes	Yes



## Appendix 12 - Patient perception of readiness for discharge quantitative studies

RefID	Author Year Country	Design	Sample	Sample age	Outcomes at discharge	Outcomes later	Instruments	RHDS %	Yes, No %	Setting
PP1	Weiss 2006, USA	Quantitative	Patients, Medical, Surgical, Parents & Post-partum. (n=365)	Med/Surg Pts M52.9 (SD15.3), Post-partum M29.2 (SD6.1), Parents M35 (SD8.7)	Perception of readiness was higher among patients who reported living with an adult support person, had adequate educational preparation for discharge and were more involved in their care coordination.	3 weeks; patients with higher perception of readiness at discharge had better coping abilities and were less likely to make calls for support or advice.	RHDS, QDTS, PDCDS	M ranged 6.5 to 9.2. M for total scale was 8.0, and subscale M from 7.1 to 8.5	96% = Ready, 4% = not ready	Acute
PP2	Weiss <i>et al.</i> 2007, USA	Quantitative	Patients, Medical, Surgical, (n=135)	A mean age of 53.4 (SD 15.0)	Age is a significant indicator of discharge readiness. Effective teaching delivery and good care co-ordination increased RHDS scores.	3 weeks; Living alone was the most significant predictor of post discharge service utilisation and was associated with a threefold increase in the number of calls to family and friends for support. Those who perceived themselves to be not ready had more coping difficulties at 3 weeks.	RHDS, QDTS, PDCDS	RHDS M = 8.0 (SD = 0.9), range of M = 6.1 to 9.1, QDTS M = 7.6 (SD = 1.4), range of M = 4.9 to 8.9, PDCDS M = 2.4 (SD = 1.0), range of M =	93% = Ready, 3% = not ready	Acute
PP3	Bobay <i>et al.</i> 2010, USA	Quantitative	Patients, Medical, Surgical, (n=1449)	1,108 were >55 years old. The age group 55–64 = 22% of the sample, 65–74 was 18%, 75–84 was 15%, and 85 and older was 4%.	Between 18% and 24% of older adult patients had low levels of readiness for hospital discharge. Quality of discharge teaching was associated with patients feeling ready to go home in the <85 year old patient.	30 days; When patients >85 years old had poor support post discharge 30% of them were either readmitted, had an unscheduled physician or ED visit. Almost 45% of the oldest patients (>85) with a perceived coping ability of <7 were readmitted within 30 days.	RHDS, QDTS	18% to 24% of patients age ≥55 years had low levels of readiness	95% to 100% of all patients = ready	Acute
PP4	Weiss <i>et al.</i> 2011, USA	Quantitative	Patients, Medical, Surgical & Unit level staff, (n=1449)	Not specified	Patients reported a high level of discharge readiness (M=8). Higher information and knowledge levels among patients were associated with a higher perception of readiness.	30 days; Readmission rate was 11.9%. An additional 5% had ED visits without admission. Non-overtime RN staffing decreased the odds of readmission.	RHDS, QDTS	RHDS = M8 (SD=1.4)	n/a	Acute
PP5	Coffey & McCarthy 2013, Ireland	Quantitative	Patients, Medical, Surgical, (n=335)	>65yrs	Patients >80 years experienced lower levels of perceived readiness (M=6.83). Coping ability scores were lowest in the >80 year olds (M=7.33) and they had the lowest knowledge scores (M6.67). <20% had referrals to community supports other than the PHN or GP. 80% did not have informal support in place.	6 weeks; GP services were used by 90% and PHN visits increased. Informal support had increased (4–12%). Less time in hospital increased support after discharge. 25% were readmitted and those >80 years who were initially an emergency admission were four times more likely to be readmitted within six weeks.	RHDS	Patients were ready for discharge (M=7.31 SD 1.13)	93.7% = Ready, 2.3% = not ready	Acute
PP6	Brent & Coffey 2013, Ireland	Quantitative	Patients - Post Hip Surgery, (n=50)	>75 years	Physical and emotional readiness was low at M6.68. Those living alone had lower scores at M6.09. Knowledge had a low score of M6.29. Readiness scores decreased as age increased and those who lived with family had a higher perception of readiness.	n/a	RHDS	RHDS 6.68 (SD 1.123).	88% = ready	Acute
PP7	Weiss <i>et al.</i> 2014, USA	Quantitative	Patients, Medical, Surgical, Nurses (n=251)	Not specified	When nurses assessed patients to have low discharge readiness there was a six to nine fold increase in readmission.	Non-overtime nurses reduce readmission rates	RHDS	15% of patients low readiness		Acute
PP8	Schmocker <i>et al.</i> 2015, USA	Quantitative	Patients, Medical, Surgical, (n=318)	M 62.3 years (interquartile range 52.5 to 70.8 years)	There was a statistically significant relationship between patients reported readiness and physician communication.	30 days; Patients less ready for discharge had an 18.2% readmission rate compared with those who perceived themselves as ready having an 11.4% readmission rate.	Question had 5 responses: very poor, poor, fair, good, very good.	n/a	n/a	Acute
PP9	Lau <i>et al.</i> 2016, Canada	Quantitative	Patients, Medical, (n=495)	62 years (SD 19)	23% of patients were not ready. Age was a significant predictor of poor discharge readiness.	30 days; 16% were readmitted, 3% had died and 26% had attended the ED.	Yes/No on a 0 to 10 scale 77% = ready	n/a	23% not ready	Acute
PP10	Kaya <i>et al.</i> 2018, Turkey	Quantitative	Patients, Medical, Surgical, (n=1,601)	Unready pts M62.3 (17.25D) years V's ready pts M53.1 (18.4 SD) years	40% of patents were not ready for discharge	30 days; death and negative outcomes were higher (p < .01) for patients who were discharged without being ready.	RHDS	40% = unready	n/a	Acute
PP11	Mabire <i>et al.</i> , 2019, Switzerland	Quantitative	123 surgical, medical and mixed units in 23 hospitals n= 1833 RN and n=1755 pts	Pts age M67.0 (SD15.8)	Patient readiness was higher in patients who received discharge teaching, in units where nurses had higher levels of experience. In larger medical units, patient readiness for hospital discharge was lower.	n/a	The nurse survey 177 items, the patient survey 37 items and the unit survey 9 items	62% ready	n/a	Acute

## Appendix 13 – Patient perception of readiness for discharge qualitative studies

RefID	Author Year Country	Design	Sample	Sample age	Outcomes at discharge	Outcomes later	Instruments	RHDS %	Yes, No %	Setting
PP12	Neiterman <i>et al.</i> , 2015, Canada	Qualitative	High risk Patients (n=17 >70 years) & caregivers (n=19)	Pts >70 years	Those who had the support of family members were more successful in adapting to the transition.	The period post discharge is chaotic not just medically but socially	Interview between 2 to 5 weeks	n/a	n/a	Acute to home
PP13	Satink <i>et al.</i> 2015, Netherlands	Qualitative	Patients/Stroke Survivors (n=16)	(n=12) >65yrs	The stroke survivors stated they could not have managed without their relatives.	3 months; Patients stated they could not have managed without their relatives. Patients indicated that they required more support in the immediate discharge period, in the areas of managing daily care and support to cope with changes in their lives.	Focus groups	n/a	n/a	Rehab to home
PP14	Allen <i>et. Al</i> 2018, Australia	Qualitative	Medical Patients (n=13) & caregivers (n=7)	All pts >70years. Cgs > 18 years	1. Needing to become independent 2. Supportive relationships with carers. 3. Caring relationships with health-care practitioners. 4. Seeking information. 5. Discussing and negotiating the transitional care plan. 6. Learning to self-care.	Interviews took place after 1 week	Semi structured interviews	n/a	n/a	Acute & Rehab
PP15	Mitchell <i>et al.</i> 2018, USA	Qualitative	34 focus groups (103 patients, 65 caregivers) and 80 interviews (35 patients, 45 caregivers)	Pts M61years & Cgs M56 years	(1) feeling cared for and cared about by medical providers, (2) having unambiguous accountability on the part of the health care system, and (3) feeling prepared and capable of executing the care plan upon discharge.	n/a	Focus groups and individual interviews	n/a	n/a	Acute



## Appendix 14- Healthcare providers' practices

STUDIES REVIEWING DOCUMENTATION AND REFERRALS							
RefID	Author Year Country	Design	Sample	Sample Type	Outcomes	Comment	Setting
HCP 1	Foust, 2007, USA	Qualitative	Nurses (n=8) & Patients (n=7)	Staff of Gynaecological surgery pts	Discharge preparation was combined with other nursing activities and a gap between observed and documented discharge planning efforts existed	Teaching, communication and planning missing from the notes	Acute
HCP 2	Dunnion & Kelly, 2008, Ireland	Mixed method	PHNs (n = 55); GPs (n = 32); practice nurses (n = 18); ED doctors (n=11) and RGNs (n=19)	ED and primary care staff	Poor communication with post discharge support system. Abrupt and late evening discharges problematic	96% of PHNs and 93% of GPs agreed there was a need to increase and improve the level of referral	Acute
HCP 3	Connolly <i>et al.</i> , 2010, UK	Mixed method	All staff (n= 455)	Staff involved in hospital discharge	Documentation declared satisfactory by 70% of respondents. 75% agreed that waiting for one part of the discharge plan to be completed caused delays. 72% agreed that moving patients from one ward to another could delay discharge	Opinion was split on the question of whether patients and carers were involved in all stages of discharge	Acute
HCP 4	Oliveira <i>et al.</i> , 2011, Portugal	Quantitative	Nurses	Documentation regarding the caregiver	Caregivers had poor knowledge & poor skill	56.9% of patient records have no documented communication on discharge teaching of the informal or family caregiver	Acute
HCP 5	Hesselink <i>et al.</i> , 2012, Netherlands	Qualitative ; Netherlands, Spain, Poland, Italy and Sweden were involved in this project	Interviews (n=192) & 26 focus groups with 53 patients (>18 years), 46 hospital physicians, 38 hospital nurses, 39 GPs and 16 community nurses.	Handovers to primary care team about Patients (>18 years)	1. Health provider prioritisation of discharge consultations; 2. Decision-making within the discharge process; 3. Care provider anticipation of patient-specific needs and preferences; and 4. Organisational factors.	Discharge information given irregularly, consequently, patients, especially the elderly, are often unaware of the importance of the information provided. Insufficient instructions concerning their follow-up	Acute
STUDIES REVIEWING DISCHARGE PLANNING PROGRAMMES							
	Author Year Country	Design	Sample	Sample Type	Outcomes	Comment	Setting
HCP 6	Shyu <i>et al.</i> , 2008, Taiwan	Quantitative RCT	Caregivers (n=72)	Pts > 65years Stroke	After 3 days the intervention groups preparation significantly improved. A significant improvement in both groups was noted one month after discharge with a significantly higher satisfaction score in the intervention group	Discharge planning program targeting > 65years	Acute
HCP 7	Shyu <i>et al.</i> , 2010, Taiwan	Quantitative	Caregivers (n=72)	Pts > 65years Stroke	0 patients admitted to long term care in the intervention group compared to the control group where 6 patients were admitted to long term care during months 6-12	Discharge planning program targeting > 65years	Acute
HCP 8	Saleh <i>et al.</i> , 2012, USA	Quantitative	Patients (n= 292) V (n=153)	Pts > 65years Medical surgical	Intervention groups had less readmissions after 30 days and there was monetary savings	Post care transition program targeting > 65years	Acute
HCP 9	Knier <i>et al.</i> , 2015, USA	Quantitative	Patients (n=31)	Rehabilitation unit > 18 years	RHDS indicated that perceived support improved (pre M 8.59, SD1.53 and post M9.24, SD.94) and the QDTS showed significant improvements in discharge teaching (pre M7.96, SD1.43, post M8.8, SD1.14)	The Discharge Process Acute Rehabilitation Transition (DePART) tool	Rehab
HCP 10	Weiss <i>et al.</i> , 2019, USA	Quantitative	33 hospitals 1 intervention unit and 1 control unit in each. Patients (n=144,868)	Medical & Surgical > 18 years	ED rates decreased with all protocols RN-RHDS increased from 8.14 (out of 10) during READI1 to 8.20 with READI2 and to 8.60 with READI3; PT-RHDS increased from 8.42 during READI2 to 8.64 with READI3.	Readiness Evaluation and Discharge Intervention (READI) READI1, READI2, READI3	Acute

## Appendix 15- Caregiver concerns and experiences of hospital discharge

RefID	Author Year Country	Design	Sample	Sample Type	Design type	Results	Comment	Setting	Time	Researcher?
CG 1	Boughton & Halliday, 2009, Australia	Qualitative	Caregivers & patients	Caregivers various ages (n=7) & patients various ages >17years (n=7)	Descriptive qualitative analysis	1. Uncertainty through lack of preparation for discharge; 2. Uncertainty through lack of information and; 3. Uncertainty of being at home	GP & Pharmacy main sources of assistance	Acute	Approx 5 days post discharge	Nurses
CG 2	Rydeman & Törnkvist, 2010, Sweden	Qualitative	Caregivers & patients	Caregivers various ages (n=12) Patients >65 years diverse medical & surgical	Grounded theory	1. Caring issues 2. Activities of daily living 3. Where to turn.	Caregivers interviewed in the presence of the patient	Acute	4 to 6 weeks post discharge	Nurses
CG 3	Fitzgerald <i>et al.</i> , 2011, Australia	Qualitative	Caregivers	Caregivers (n=25) caring for 7 age patient with dementia	Qualitative constructivist design	1. Insufficient communication; 2. Inadequate preparation for discharge 3. Undervaluing the family carer as a resource.	n/a	Acute	Within 2 months	Nurses
CG 4	Perry & Middleton, 2011, Australia	Mixed Method	Caregivers	Caregivers (n=32) (mostly spouses or partners) caring for patients (age M= 63) with stroke	Quantitative descriptive	22% had an absence of knowledge. 1. Stroke as a family affair 2. Changed personality, roles and relationships 3. Uncertainty and anxiety 4. Conflicted attitudes	Modified Barthel, Hospital records, Carer assessment scale, Knowledge of stroke scale, Sense of competence questionnaire, Carer satisfaction scale.	Acute	1 to 3 months	Nurses
CG 5	Gustafsson & Bootle (2013) Australia	Qualitative	Caregivers & patients	Caregivers (n=5) mean age not clear & patients (n=5) mean age 65	Descriptive qualitative analysis	1. The purpose of rehab 2. Life is different now 3. Looking to the future.	The family conference was important	Acute	1 month	Occupational Therapists
CG 6	Young <i>et al.</i> , 2014, USA	Qualitative	Caregivers	Caregivers (n=14) mean age 63, patients mean age 66	Grounded theory	Crisis, Traumatic, pressure, poor communication.	No instrument exists to assess caregivers	Rehab to home	3 weeks and 3 to 6 months later	Nurses
CG 7	Ågård <i>et al.</i> , 2015, Denmark	Qualitative	Caregivers	Caregivers of ICU patients between the ages of 25-70	Grounded theory	Caregivers struggled, huge uncertainty	GP main sources of assistance	Acute	3 & 12 months	Nurses
CG 8	Coleman & Roman 2015, USA	Qualitative	Caregivers	Caregivers Focus groups (n=4). Patients declared elderly but age unclear	Grounded theory	Felt their presence triggered annoyance, overwhelmed	Need one single professional,	Acute	within 3 months	Medicine
CG 9	Toye <i>et al.</i> 2016, Australia	Quantitative	Caregivers	Pts ≥70 years Intervention group n=77. Control group n=86	RCT	Preparedness to care improved significantly	Further Enabling Care at Home program.	Acute	3 telephone contacts; 9 days, 24 days, 40 days	Nure, Pharmacy, Public Health & Physiotherapy
CG 10	Rustad <i>et al.</i> 2017, Norway	Qualitative	Caregivers	Caregivers 47 to 80+ Pts ≥80years	Descriptive exploratory & content analysis	Next of kin balance multiple tasks during older relatives' care transition	Information they were given was incomplete	Acute	2 weeks approx	Nurses
CG 11	Schwartz <i>et al.</i> 2019, USA	Qualitative	Caregivers	n= 13 Cgs n=26 interviews Cgs M68.2 years and Pts M63.2 years	Descriptive exploratory & Thematic analysis	1. caregiver and patient wellness are connected 2. caregivers' struggle with control issues 3. challenges in communication with health professionals	Cancer specific issues as well as regular caregiving issues.	Acute	Interviews via phone or in person at 1 and 2 weeks	Nurses

## Appendix 16 - Ethical approval

 <div style="display: inline-block; vertical-align: middle;"><b>UCC</b> Tel: + 353-21-490 1901 Fax: + 353-21-490 1919</div>	<div style="text-align: right;"><b>COISTE EITICE UM THAIGHDE CLINICIÚIL</b> <b>Clinical Research Ethics Committee</b></div> <div style="text-align: right; margin-top: 10px;">Lancaster Hall, 6 Little Hanover Street, Cork, Ireland.</div>
<div style="display: flex; justify-content: space-between;"><div><b>Cóláiste na hOllscoile Corcaigh, Éire</b> <b>University College Cork, Ireland</b></div><div></div></div>	
<div style="display: flex; justify-content: space-between;"><div>3rd March 2017</div><div>Our Ref: ECM 4 (w) 07/03/17</div></div> <div style="margin-top: 10px;">Dr Alice Coffey Senior College Lecturer Catherine McAuley School of Nursing &amp; Midwifery University College Cork Brookfield Health Sciences Complex College Road Cork</div> <div style="margin-top: 10px;"><b>Re: Exploring the readiness of caregivers for the discharge of the older adult from hospital.</b></div> <div style="margin-top: 10px;">Dear Dr Coffey</div> <div style="margin-top: 10px;">Approval is granted to carry out the above study at:</div> <div style="margin-left: 40px; margin-top: 5px;">➤ Ballincollig Community Nursing Unit.</div> <div style="margin-top: 10px;">The following documents have been approved:</div> <div style="margin-left: 40px; margin-top: 5px;">➤ Cover letter ➤ Application form signed 9<sup>th</sup> February 2017 ➤ Study Protocol ➤ Insurance Details ➤ CV for chief investigator ➤ Letter to Director of Nursing ➤ Participant Information Leaflet ➤ Consent Form ➤ Study Questionnaire ➤ Interview Questions.</div> <div style="margin-top: 10px;">We note that the co-investigator involved in this study will be:</div> <div style="margin-left: 40px; margin-top: 5px;">➤ Eileen Galvin, Clinical Nurse Manager.</div> <div style="margin-top: 10px;">Yours sincerely</div> <div style="margin-top: 20px;"> Professor Michael G Molloy Chairman Clinical Research Ethics Committee of the Cork Teaching Hospitals</div> <div style="margin-top: 30px; font-size: small;"><p>The Clinical Research Ethics Committee of the Cork Teaching Hospitals, UCC, is a recognised Ethics Committee under Regulation 7 of the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004, and is authorised by the Department of Health and Children to carry out the ethical review of clinical trials of investigational medicinal products. The Committee is fully compliant with the Regulations as they relate to Ethics Committees and the conditions and principles of Good Clinical Practice.</p></div>	
Ollscoil na hÉireann, Corcaigh - National University of Ireland, Cork.	

## Appendix 17 - Access letter

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Eileen Galvin CNM  
Ballincollig Community Nursing Unit,  
Murphy Barracks Road,  
Co. Cork  
[113115693@umail.ucc.ie](mailto:113115693@umail.ucc.ie)  
Mobile; 087 9757237  
5<sup>th</sup> Feb 2017

Ms Liz O'Connell  
Director of Nursing  
Ballincollig Community Nursing Unit  
Murphy Barracks Road  
Co Cork

Title of Study: Exploring the readiness of caregivers for the discharge of the older adult from hospital

Researcher: Eileen Galvin RN RM BSc

Dear Ms O'Connell,

I am currently undertaking a Masters by Research in Nursing in the University College Cork (UCC). My proposed study is a qualitative study which aims to explore the readiness of caregivers for the discharge of the older adult from hospital. I am requesting permission to conduct this study in your nursing home and with your consent to recruit caregivers. I propose to conduct semi-structured interviews with approximately ten caregivers who accompany convalescent patients from the acute setting. These interviews will be voice recorded.

All participants will be given a letter of explanation and asked to sign a consent form. Participants will be advised that they have the right to withdraw from the study at any time and their data will not be included in the study. The four ethical principles of non-maleficence, justice, autonomy and beneficence will be held paramount. Anonymity and confidentiality of participants will be protected at all times and all personal details and the study's location will be kept anonymous at all stages of the research. The research data will be stored in a locked cabinet, with any electronic data stored on a computer and password protected.

I would be grateful if I could conduct the interviews in a room within the nursing home where the participants will feel comfortable and confidentiality can be maintained. It is hoped this research will add to the body of knowledge with regard to hospital discharge therefore contributing to evidence based practice.

I will be guided by my research supervisor from UCC throughout the study, Dr Alice Coffey. If you would like to discuss this further, please contact me by phone or email (see below).

Yours sincerely,

Eileen Galvin RN RM BSc

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## Appendix 18 - Participant information leaflet

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### **Exploring the Readiness of Caregivers for the Discharge of the older adult from Hospital.**

My name is Eileen Galvin and I am currently undertaking a Masters by Research in the Catherine McAuley School of Nursing and Midwifery, University College Cork (UCC). I am seeking your assistance with the above research.

**About the Study:** This study will explore with you your experience as a caregiver during hospital discharge of the patient, so that more is known about your needs as a caregiver during that time. This research will be used to inform those involved in hospital discharge about caregiver concerns.

**Who can participate in this study?** Caregivers 18 years or older who are the main caregiver of the patient who is discharged from hospital.

**Do I have to say yes?** Participation in this research study is voluntary and there is no obligation to take part. Anonymity is guaranteed.

**What will happen to me?** If you decide to take part, you will be interviewed privately and asked questions about your experience as a caregiver during hospital discharge. The interview will be voice recorded with your permission.

**Consent:** You will be asked to complete a consent form

**How long will the interview take?** The aim is to keep the interview as short as possible so 30 minutes approximately and you may terminate the interview at any time.

**How will I be able to access results of this study?** The results of this study will be published in the nursing and healthcare literature. If you would like a copy of the results I will be happy to provide one for you.

**What do I do now?** If, having read this information leaflet, you are willing to participate in the study; we will proceed with the interview at your convenience. Thank you for your time and participation is greatly appreciated.

#### **Researcher contact details:**

Eileen Galvin Clinical Nurse Manager 1  
Ballincollig Community Nursing Unit,  
Murphy Barracks Road, Ballincollig, Co Cork.  
Phone 087 9757237  
E-mail; [113115693@umail.ucc.ie](mailto:113115693@umail.ucc.ie)

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## Appendix 19 - Caregiver semi-structured interview questions

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### *Exploring the Readiness of Caregivers for the Discharge of the older adult from Hospital*

Researcher:

Eileen Galvin

Date: \_\_\_\_\_ Interview Number: \_\_\_\_\_

#### Semi-structured Interview Questions

- Tell me how you feel about being an informal caregiver?
- Tell me about yourself, how are you dealing with your own health needs and being a caregiver?

Would you like to elaborate, can you tell me more?

- Can you tell me about leaving the acute hospital how did you feel?

Any concerns?

- Please tell me about the support you received in hospital?

And at home?

- What information or knowledge was important for you to know as a caregiver at the time of discharge from the acute hospital?

Anything else?

- And now after hospital discharge, is there anything else you needed or required before leaving the acute hospital?

The interviewer will provide the interviewee with the opportunity to add any thoughts, information, or questions at this point.

## Appendix 20 – Table of data analysis procedure

Content Data Analysis					
Phase	Step	What is this?	How?	Why?	Reference
Preparation	Transcribe the interviews verbatim. Read and reread the interviews.			To become familiar with the text.	Elo and Kyngäs (2008)  Giorgi (1985); Pope et al. (2000); Elo and Kyngäs (2008); Wertz (2011); Miles et al. (2014); Parahoo (2014)
	Create meaning units.	A meaning unit is defined as words sentences or paragraphs containing content related to the research question, this guides the selection .	Using Excel create a table with each participant have their own section.	To assist with triangulation and therefore methodological rigour as it is possible to later give the answer as to why a decision was made.	Graneheim and Lundman (2004); Elo and Kyngäs (2008); Vaismoradi et al. (2013)
Organisation	Begin to code the data by opening sub-categories.	A sub-category is a group of meaning units that share the same values, messages or purpose.	This stage refers to condensing text while preserving the core by opening as many sub-categories as is necessary.	This is the beginning of sorting the large amount of data generated by the interviews into sub-categories.	Graneheim and Lundman (2004); Elo and Kyngäs (2008); Vaismoradi et al. (2013);
	Name the sub-categories.	Names define the characteristics or attributes of the meaning units.		To assist with assigning meaning units and gathering similar data into sub- categories.	Elo and Kyngäs (2008); Miles et al. (2014)
	Make notes.	Note making assists with triangulation and methodological rigour as it is possible to later give answers as to why decisions were made.	Either hand written or in a separate column for excel or in the areas provided in the qualitative data analysis programmes.	To give reasons as to why meaning units were put into which sub-F20categories.	Reid and Gough (2000); Elo and Kyngäs (2008); Colorafi and Evans (2016)
	Look for patterns and similarities.		Ask questions.	A pattern may be emerging or you may be asking yourself a question which can help with decisions made later.	Giorgi (1985); Pope et al. (2000); Elo and Kyngäs (2008); Wertz (2011); Miles et al. (2014); Parahoo (2014)
	Reduce the amount of sub-categories.	Group similar sub-categories together.	Some enlarge and some become irrelevant.	To develop solid categories.	Elo and Kyngäs (2008); Colorafi and Evans (2016)
Reporting	Report the findings.	Describe in writing the most effective truthful level of generality.	Report the categories that emerged by summarising and effectively using excerpts.	To disseminate knowledge.	Elo and Kyngäs (2008)
		The end result is a description of the patterns that emerged with a deeper insight .			Sandelowski (2000); Graneheim and Lundman (2004); Sandelowski (2010)
		The aim is to attain a condensed and broad description of the phenomenon in categories or themes.			Elo and Kyngäs (2008)

## Appendix 21 – Example of coding

### Category - Physical Readiness

Participant Code	Meaning unit	Condensed meaning unit	Sub-category
P3	“Well I suppose twas landed on me d’you know that kind but as I say I work and then d’you know...I have a brother dicapped well he’s with care like but I bring him out every weeks as well like and but what can you do like? You et a person you know”.	“Well I suppose twas landed on me d’you know”	Overwhelmed
P4	“We don’t know what we’re doing we actually haven’t a clue what we’re doing. Dementia is a terrible disease”.	“We don’t know what we’re doing, we actually haven’t a clue what we’re doing. Dementia is a terrible disease”.	Overwhelmed
P5	“You see physically I’m not able either cause I have breast cancer. I’m only you know what I mean coming out of that. I’m still tired like I went back to work in September and I had to do an awful lot so I was full on since September and then Christmas and I went back after Christmas and I was wrecked. I knew I was in over my head it’s after catching up with me and then I said I have	“I’m still tired like, I went back to work in September and I had to do an awful lot, so I was full on since September and then Christmas.... and I went back after Christmas and I was wrecked. I knew I was in over my head, it’s after catching up with me and then I said I have to back off a small	Overwhelmed

Participant Code	Meaning unit	Condensed meaning unit	Sub-category
	to back off a small bit so I had just started to back off and so....I'm exhausted".	bit...so I had just started to back off and.....so I'm exhausted".	
P8	"Well what you call it when it all kicked off ... when it all happened first I'd say we were all overwhelmed cause she was a very fit woman and active and she just went down all of a sudden ya... well her mobility is kinda gone to be honest because sure waiting for the hip..."	"I'd say we were all overwhelmed, cause she was a very fit woman and active and she just went down all of a sudden ya... her mobility is kinda gone to be honest".	Overwhelmed
P1	"The house is torn up at home cause we've had to break through the back kitchen wall to make a handicapped shower unit and toilet, we are going to have to switch the upstairs furniture down and the downstairs furniture up and you see the downstairs room is an exact image of the upstairs room so my husband had an idea, that how bout we put the bed in exactly the same position so on her left hand side will be the window and her dressing table will be the same"	"The house is torn up at home cause we've had to break through the back kitchen wall to make a handicapped shower unit and toilet, we are going to have to switch the upstairs furniture down and the downstairs furniture up and you see the downstairs room is an exact image of the upstairs room so my husband had an idea, that how bout we put the bed in exactly the same position so on her left hand side will be the window and her dressing table will be the same"	Cleaning & Renovating
P5	I done a big clean up at home but, I haven't moved anything (ya I know what you mean) strategic like, I dumped old clothes and stuff I made it actually easier to get at stuff so when you go home, but I'm afraid that he's	"I done a big clean up at home but, I haven't moved anything strategic like, I dumped old clothes and stuff I made it actually easier to get at stuff so when he goes home...and now I'm	Cleaning & Renovating

Participant Code	Meaning unit	Condensed meaning unit	Sub-category
	going to go home and he'll be afraid to come out, so he's gonna need like, I kind of said to him like an assist dog, I did mention guide dog but that didn't go down too well, that was when he was in hospital. No. Cause I had said that to them and we are in the process , I mean, (ya) now I'm watching my phone cause the carpets are coming today and the new bed cause he needed a new bed (chatting about cleaning and doing up the house when someone is in hospital ). I mean I spent all day Saturday cleaning up the house. (And you shouldn't be...) I have lymphodema as well in my breast which is worse ... (chatting about) talking about her breast hopping, (gave advice about it).	watching my phone cause the carpets are coming today and the new bed cause he needed a new bed . I mean I spent all day Saturday cleaning up the house. I have lymphodema as well in my breast which is worse”.	
P9	Tomorrow now I have to spend time looking for a commode... we've no toilet downstairs (ok) and we've a very deep stairs to go up. (And who's helping you to get that?) I'll be there on my own Im going to the medical centre in the health centre”.	“Tomorrow now I have to spend time looking for a commode... we've no toilet downstairs and we've a very steep stairs to go up....I'll be there on my own I'm going to the medical centre”.	Cleaning & Renovating
P1	“You see another thing we had to deal with was the clothing, if you saw what came off her when she came into the hospital. Twas like 50 years old. She had manky	“You see another thing we had to deal with was the clothing, if you saw what came off her when she came into the hospital. Twas like 50 years old. She	Difficulties Experienced

Participant Code	Meaning unit	Condensed meaning unit	Sub-category
	underwear...so we were trying to get her to wear a pants and she didn't know about probably cause it wasn't very lady like my sister finally convinced her... she's like a fish out of water.. and she's going back to her skirts as soon as she goes home... but she can't bend down... she is becoming more difficult".	had manky underwear...so we were trying to get her to wear a pants and she didn't know about probably cause it wasn't very lady like my sister finally convinced her... she's like a fish out of water...and she's going back to her skirts as soon as she goes home... but she can't bend down... she is becoming more difficult"	
P1	"And you see I'm after washing all her jumpers because they needed it, as she wears them and puts them back into the press and they were all once and twice and three times worn (laughing) and I said Mam your jumpers are lovely I conditioned them. What did you do with my jumpers there were none of them dirty! And the whole bed you should have seen it! It was like a nest made by birds, layers upon layers upon layers of furry things and socks and bed cardigans you name it. I said I'd throw them out and I'm going to get her a lovely 14.5 tog quilt my sister says don't! Don't throw them out. I did throw the pillow out, she's going to kill me when she finds out, pillows needs to be hygienic you know, now it wasn't that it was dirty	"And you see I'm after washing all her jumpers because they needed it, as she wears them and puts them back into the press and they were all once and twice and three times worn...And the whole bed you should have seen it! It was like a nest made by birds, layers upon layers upon layers of furry things and socks and bed cardigans you name it. I said I'd throw them out and I'm going to get her a lovely 14.5 tog quilt my sister says "don't! Don't throw them out". I did throw the pillow out she's going to kill me when she finds out" (P1).	Difficulties Experienced

Participant Code	Meaning unit	Condensed meaning unit	Sub-category
	but it was do you know the way children go around with their favourite blanket and you'd love to take it off them and say I'll wash that there for you love".		
P2	"Our farm is very busy like and whatever so I'd only have the middle hours in the day kind of like and so even like she is coming to me now on Friday and but (big breath) long term I just wouldn't be able to... sustain it like no because we start around half seven in the morning like and I am back then maybe half eleven twelve o clock and this time of year like and we start then again at six and I mightn't be back then again until like til nine o clock in the evening and there's other stuff to be done in the meantime..".	"Our farm is very busy like and whatever so I'd only have the middle hours in the day kind of like and so"	Difficulties Experienced
P5	"I'm afraid that he's going to go home and he'll be afraid to come out, he can read it but you see it's his periphery vision so when he's walking he can't (I know) like they said it's not unmanageable but he will need a lot of.. we're lucky we've a good sense of humour at home and I was saying to the girls we'll have to call to granddad everyday and take him for a walk, ye always wanted a dog well...	"I'm afraid that he's going to go home and he'll be afraid to come out, so he's gonna need like, I kind of said to him like an assist dog, I did mention guide dog but that didn't go down too well, that was when he was in hospital"	Difficulties Experienced

Participant Code	Meaning unit	Condensed meaning unit	Sub-category
	cause i don't want him cause he's always had such a young heart and he's a big strong man and he always loved sweet things and I say to him this is an opportunity now to go walking.....but my biggest fear is that he'll get too heavy and his knees will go (ya) and there will be no way to manage him then... I kind of said to him like an assist dog, I did mention guide dog but that didn't go down too well, that was when he was in hospital".		
P2	"Aamm I just couldn't do it like the whole time any way like that it it physically I wouldn't be able to so aamm we're kind of hoping that she will recover some bit and go back home and aamm.. long term I just wouldn't be able to... sustain it like no because we start around half seven in the morning like and I am back then maybe half eleven twelve o clock and this time of year like and we start then again at six and I mightn't be back then again until like til nine o clock in the evening and there's other stuff to be done in the meantime.."	"Long term I just wouldn't be able to... sustain it like no, because we start around half seven in the morning like and I am back then maybe half eleven twelve o clock and this time of year like and we start then again at six and I mightn't be back then again until like til nine o clock in the evening and there's other stuff to be done in the meantime.."	Sustaining Caregiving Long-term
P3	"Now they are going into the local town, you see she goes to a local community hospital for respite but it all happened a few years ago he wouldn't stay on his own at	"D'you know now you've no idea now like the two of them like d'you know they're like children the	Sustaining Caregiving Long-term



Participant Code	Meaning unit	Condensed meaning unit	Sub-category
	<p>home and he has to go in with her but now he's staying... This time cause he has no choice. And aamm so... "Im not taking him on at all... cause I've a load done for them down through the years.. "D'you know now you've no idea now like the two of them like d'you know they're like children the two of em. Looking at it now it's going to get tough going like, I don't know about it, I'll see".</p>	<p>two of em...looking at it now it's going to get tough going like, I don't know about it, I'll see...."</p>	

## Appendix 21 – Example of coding

### Category – Caregivers Psychological Readiness

Participant Code	Meaning unit	Condensed meaning unit	Sub-category
P1	“I suppose I’d be, being honest with you at a time like this in a family, you don’t think...”	“I suppose I’d be, being honest with you at a time like this in a family, you don’t think...”	Coping
P4	“Like we’re fine. We’re trying to do what’s best for mum. Aamm she made us all promise I suppose a couple of years back that we’d never put her in a nursing home so, we’re trying our best like but looking after her ourselves just isn’t enough so we’re getting somebody else in as well so we’ve been doing a rota”	“Aamm, she made us all promise I suppose a couple of years back that we’d never put her in a nursing home so, we’re trying our best like but looking after her ourselves just isn’t enough so we’re getting somebody else in as well so we’ve been doing a rota”	Coping
P5	“Now I still believe he can live at home like, I’m trying to you know, and I said it to him there like, cause when you have your own house you’re going to have your own surroundings and you’ll know where everything is.. (big sigh)”	“Now I still believe he can live at home like, I’m trying to you know...and I said it to him there like, cause when you have your own house you’re going to have your own surroundings and you’ll know where everything is...”	Coping

Participant Code	Meaning unit	Condensed meaning unit	Sub-category
P6	“Sure you just have to do it and that’s it. Do you know you just get on with it.”	“Do you know you just get on with it”	Coping
P8	“Well it’s hard going now at times definitely cause we’d be trying to do what’s best for Mam as well”	“Well it’s hard going now at times definitely”	Coping
P1	“I was very concerned last night cause my sister rang me and she said she’s in bits, today is Tuesday I was in on Sunday and Mam was so positive she said anything that’s needed of me now in the future im going to do it”	“I was very concerned last night cause my sister rang me and she said she’s in bits”	Concerns & Worries
P1	“It made me feel very, very, very sad; to see my mother loose so much cause she was always praised for her complete independence. And the closer it gets to gaining back her independence the less resolve she’s showing, cause my husband put his finger on it cause from the time she went into the [hospital] and they really emphasised walk, walk, walk, last Saturday I asked Mam how many times are you walking up and down the corridor? Tell me the truth! Once she said once. She’s lost something there”	“It made me feel very, very, very sad; to see my mother loose so much cause she was always praised for her complete independence, and the closer it gets to gaining back her independence the less resolve she’s showing”	Concerns & Worries

Participant Code	Meaning unit	Condensed meaning unit	Sub-category
P1	“In the long term I suppose... we’re not looking at the long term. We’re taking the next stage, we’re going to be very positive about here. I’m going to give her 36hrs here because...this has a different view on rehab.. and we’ll get the hair and the opera...”	“In the long term I suppose...we’re not looking at the long term. We’re taking the next stage we’re going to be very positive about here....this has a different view on rehab... and we’ll get the hair and the opera...”	Concerns & Worries
P1	“And the closer it gets to gaining back her independence the less resolve she’s showing, cause my husband put his finger on it cause from the time she went into the [hospital] and they really emphasised walk, walk, walk, last Saturday I asked Mam how many times are you walking up and down the corridor? Tell me the truth! Once she said once. She’s lost something there. Every time I approach it with her it’s how will I manage at home?” I think from her own perspective she is allowing helplessness set in. And I think it’s like a letting go that I would never have envisaged a year ago”	“Every time I approach it with her it’s ‘how will I manage at home?’ I think from her own perspective she is allowing helplessness set in. And I think it’s like a letting go that I would never have envisaged a year ago”	Concerns & Worries
P2	“Ya. She’ll eat one day and she won’t eat the next. Cause she’ll have the pain in her stomach again. But having said that like she’s very bad cause she’ll eat stuff I reckon she should be on a certain diet like I	“Ya, she’ll eat one day and she won’t eat the next. Cause she’ll have the pain...But having said that like	Concerns & Worries

Participant Code	Meaning unit	Condensed meaning unit	Sub-category
	reckon she shouldn't be eating stuff that's hard to digest like"	she's very bad cause she'll eat stuff I reckon she should be on a certain diet like"	
P3	"I dunno now getting out of the bed and things... but aamm... she hasn't gone to the toilet on her own now or anything in the hospital... you know so..."Now there's the two of them but there's some little thing....and... (breath) they have home help and she's very good to them, and all that like but aamm... she hasn't gone to the toilet on her own now or anything in the hospital... you know so..."	"I dunno now getting out of the bed and things... but aamm... she hasn't gone to the toilet on her own now or anything in the hospital... you know so..."	Concerns & Worries
	"But I'd say long term they, I would think that she'd be thinking long term that they would be better in a nursing home like that's not for me to say like that would be up to her niece"	"I think myself down the line she's only suitable for a nursing home like that's not for me to say like that would be up to her niece"	Concerns & Worries
P5	he's very blind and he's only now, like they've left him out and to be fair they did their best to try and tell him but like he really genuinely believed that they were wrong, its only there now he's going oh	"He's very blind and he's only now, like they've left him out and to be fair they did their best to try and tell him but like he really genuinely believed that they were wrong, its only there now he's going 'oh my god I can't see'... "	Concerns & Worries

Participant Code	Meaning unit	Condensed meaning unit	Sub-category
	my god I can't see. So I think maybe they should have brought him out"		
P5	"God we'll just have to wait and see and you see I go away every July"	"God we'll just have to wait and see and you see I go away every July"	Concerns & Worries
P6	"Well we are a little worried about her but sure we'll just have to deal with it and we will see how we get on now Monday... they...were worried that she wouldn't be able and she certainly wouldn't be able to go home at the moment"	"We were worried that she wouldn't be able and she certainly wouldn't be able to go home at the moment. Well we are a little worried about her but sure we'll just have to deal with it and we will see how we get on now Monday"	Concerns & Worries
P7	"Well she's ok ya just... she has come on since the weekend like she was very weak there at the weekend and they had to give her blood and all that. A bit well I suppose what I was worried about was that last year she had these lymph nodes removed from her leg and she was discharged after about a week I suppose and she was only home 3 or 4 days and she got a bad infection and was back in again for ten days. So and like those first few days she was at home she was very weak and you know..."	"What I was worried about was that last year she had these lymph nodes removed from her leg and she was discharged after about a week I suppose and she was only home three or four days and she got a bad infection... Ya the worry...the same thing like she wouldn't be able to do anything... she has come on since the weekend like she was very weak there at the weekend and they had to give her blood and all that"	Concerns & Worries

<b>Participant Code</b>	<b>Meaning unit</b>	<b>Condensed meaning unit</b>	<b>Sub-category</b>
P8	<p>“They had spoken to us before she came out of hospital cause we didn’t know what you know our short or long term plan was for Mam so they just went kind of through everything and maybe getting home help and stuff for her I suppose we’re ok now cause we know she’s here and she’ll get her physio and stuff done I suppose when she comes home we are going to be nervous worrying long term for herself will she continue her physio... we hope she will”</p>	<p>“They had spoken to us before she came out of hospital cause we didn’t know what you know our short or long term plan was for Mam so they just went kind of through everything and maybe getting home help and stuff for her. I suppose we’re ok now cause we know she’s here and she’ll get her physio and stuff done I suppose when she comes home we are going to be nervous worrying long term for herself will she continue her physio... we hope she will”</p>	Concerns & Worries

## Appendix 22 - Consent for participation in research study

<b>Study Title:</b>
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Exploring the readiness of caregivers for the discharge of their older adult relative from hospital
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**Name of Chief Investigator:** Dr Alice Coffey

**Name of Co- Investigator:** CNM Eileen Galvin

**Contact Number for Chief Investigator:** 021 490 1459

**Contact Number for Co-Investigator:** 021 4620600

My Name is Eileen Galvin and I am a nurse here in Ballincollig Community Nursing Unit and I am also undertaking a Masters by research at UCC. I am researching the area of hospital discharge and in particular the readiness of informal caregivers to take home their older adult from hospital.

In order to decide whether or not you want to be a part of this research study, you should understand enough about its risks and benefits to make an informed judgment. This process is known as informed consent. This consent form gives detailed information about the research study. When you are sure you understand the study and what will be expected of you, you will be asked to sign this form if you wish to participate.

### NATURE AND DURATION OF INTERVIEW AND PROCEEDURES:

You will be asked to participate in an interview with me (Eileen) in private. I would **like your permission to record the interview** so I can listen and write down your answers in detail later. The **information you give will be confidential** and these **recordings will not be used for any other purpose**. I will be asking you questions about the patients discharge from hospital and if you felt ready for discharge I will also ask some brief information about yourself such as your relationship to the patient, your age, where you live. There will be only one interview and you are free to terminate the interview at any stage and refuse to answer questions if you so wish. The interview will take place here in the building at a time that suits you. The interview should take approximately 30 minutes.

### POTENTIAL RISKS AND BENEFITS:

I wish to improve the area of hospital discharge in order to make the transition home as easy as possible for caregiver and patient. Your help and assistance would be greatly appreciated and again if you find the questions uncomfortable or upsetting you may withdraw from the study at any time.

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### AGREEMENT TO CONSENT

The research project has been fully explained to me. I have had the opportunity to ask questions concerning all aspects of the project. I am aware that participation is voluntary and that I may withdraw my consent at any time. I am aware that my decision not to participate or to withdraw will



not restrict my access to health care services normally available to me. Confidentiality of records concerning my involvement in this project will be maintained in an appropriate manner. When required by law, the records of this research may be reviewed by government agencies and sponsors of the research.

I understand that the investigators have such insurance as is required by law in the event of injury resulting from this research.

I, the undersigned, hereby consent to participate as a subject in the above described project conducted at Ballincollig Community Healthcare Unit. I have received a copy of this consent form for my records. I understand that if I have any questions concerning this research, I can contact the Chief Investigator listed above. I understand that the study has been approved by the Cork Research Ethics Committee of the Cork Teaching Hospitals (CREC) and if I have further queries concerning my rights in connection with the research, I can contact CREC at Lancaster Hall, 6 Little Hanover Street, Cork, 021 4901901. I understand that my anonymised data will be stored at UCC for 7 years.

**Please answer by circling yes or no**

I have read and understand the study:                      yes          no

I agree to participate in this research:

yes	no
-----	----

I agree to allow my interview to be audio-recorded:    yes        no

I grant permission for the data collected to be used in this research only:                      yes                      no

Investigator Signature: \_\_\_\_\_

Signature of Study Participant: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix 23 - Demographic data

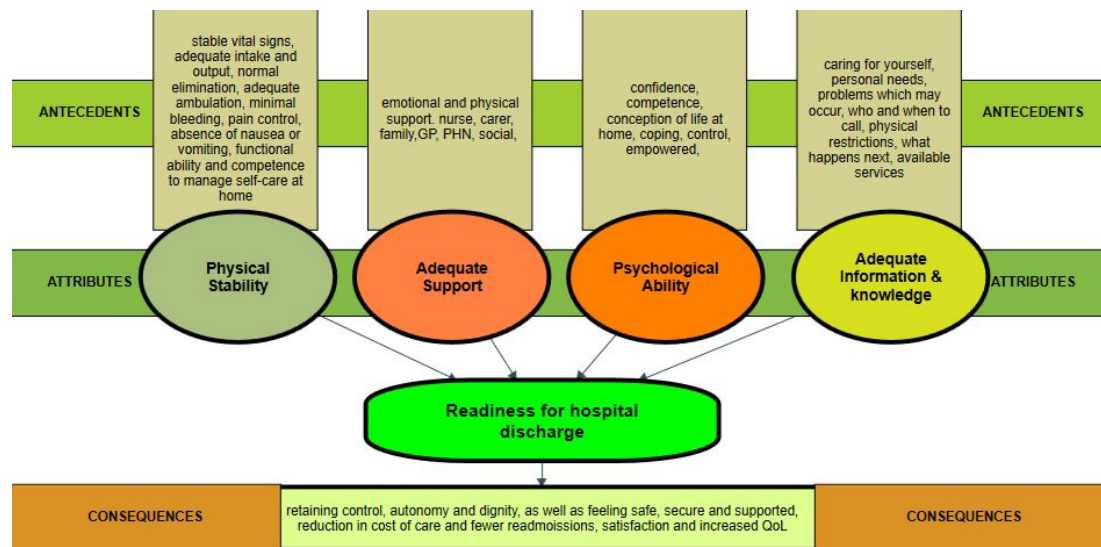
DEMOGRAPHIC DATA											
	Age	Gender	Relationship	Caregiver status	Occupation	Education	Reason for hospital admission	Planned or Emergency admission	Days in acute Hospital	Age of the patient	Patient gender
PILOT	40-49	Female	Daughter	Shares with sister	College Lecturer	Masters Degree	Dizziness, nausea & ongoing neck pain	Emergency	21 days	75	Female
Caregiver 1	60-69	Female	Daughter	Shares with sister	Retired school teacher	Degree	Fall	Emergency	48 days	95	Female
Caregiver 2	50-59	Female	Daughter	Shares with brother	Farmer	Leaving cert	Diarrohes & Pain	Emergency	22 days	85	Female
Caregiver 3	60-69	Female	Niece of late husband	Shares with a niece	Healthcare assistant	Fetac 5&6	Unwell not eating, UTI gastric ulcer, RTI	Emergency	21 days	79	Female
Caregiver 4	40-49	Female	Daughter	Shares with 2 of her 3 sisters	Bank Manager	Masters Degree	Falls and early dementia	Emergency	19 days	82	Female
Caregiver 5	40-49	Female	Daughter	Shares with 3 brothers but mostly herself	Self employed	Leaving cert	Stroke	Emergency	16 days	86	Male
Caregiver 6	50-59	Female	Daughter	Shares with 1 sister	Catering assistant	3rd Level	Total Hip Replacement	Planned	7 days	82	Female
Caregiver 7	50-59	Female	Daughter	Main caregiver but 2 brothers	Clerical position	Leaving cert	Cardiac Valve Replacement	Planned	15 days	83	Female
Caregiver 8	30-39	Female	Daughter	1 sister and 3 brothers	Childcare Assistant	Fetac 5&6	Total Hip Replacement	Planned	6 days	72	Female
Caregiver 9	70-79	Female	Spouse	Main caregiver Cares for son too	Shop Assistant	Intercert	Total Hip Replacement	Planned	6 days	74	Female

## Figures and Tables

**Table 1 – Caregiver demographics**

DEMOGRAPHICS		
	Caregivers	Patients
Age	40-79 years	72-95 years
Gender	Female n = 9	Female n = 8
	Male n = 0	Male n = 1
Relationship	Daughter n = 7 Spouse n = 1 Niece (in-law) n=1	
Education Level	Second level – Masters Degree	
Admission type	Emergency n=5	Planned n=4
Length of hospital stay	16-48 days	6-15 days
Reasons for admission	Falls, Stroke, Gastric & Intestinal issues	Total hip replacement & Cardiac valve replacement

**Figure 1 - Conceptual map of readiness for hospital discharge**



**Figure 2. Caregiver Readiness**

